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COLLABORATIVE POLICY CONSTRUCTION AND DE-INSTITUTIONALISATION:
THE CASE OF THE VALLEY VIEW CENTRE

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Abstract

This dissertation addresses the de-institutionalisation of the residents of the Valley View Centre in Moose Jaw, Saskatchewan. Using an authentic model of citizen participation, the Government of Saskatchewan partnered with citizen stakeholders to create effective policies for transitioning Valley View residents to life within the community. The closure of any institutional facility is a daunting task that rarely succeeds. This is because many governments either fail to close the obsolete facility or they merely trans-institutionalise remaining residents.

For centuries, various governments have relied on policies of institutionalisation to mitigate social problems affecting people who have disability or live in poverty. In the late 20th Century, however, many governments began to restructure their economies in a manner that included a de-construction of their welfare states. This economic restructuring necessarily involved the privatisation of state administered care and the closure of institutional care facilities. De-institutionalisation is a difficult and contentious process, which is why many governments may fail to reach goals. For instance, stakeholders and governments often have different understandings of what de-institutionalisation means and how it is achieved. Common difficulties that block transitions involve labour discontent, lack of adequate community living infrastructure, and opposition from the families of institutionalised residents. Also, the general public tends to require information to understand what de-institutionalisation is and why policies of inclusion are desirable.

The de-construction of welfare states provided various social movements for inclusion and de-institutionalisation with an opportunity to transition vulnerable people to community living. Still, many governments have failed to foster functional relationships with advocates for inclusion, or with the family members of the people who are institutionalised. In the case of the Valley View Centre, the Government of Saskatchewan chose an approach using the highest possible level of citizen participation. Not only were the stakeholders given control over the construction of policy, but the commitment to authentic citizen participation enabled all goals to be met. The example of the Valley View Centre transition is a model that may be replicated for the closure of other institutional facilities, and that may also be applied to a wide variety of policy problems.

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Dedication

For my husband Michael Baumann. Most people merely refer to him as a saint for putting up with me, but I like to refer to him as my partner and the love of my life. Everything I have achieved is because of him.

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Chapter 1

Introduction

In 1955, a ‘state of the art’ institutional facility opened in Moose Jaw, Saskatchewan. Not only was it to serve as the foundation of the architecture of care for people who have intellectual disability, but it was meant to be a source of jobs and economic stability for the people of Saskatchewan. A policy of institutionalisation had underpinned Saskatchewan’s economic organisation for much of the 20th century, and institutionalisation continued to be important to Saskatchewan’s economy for long after the province chose to adopt a policy of de-institutionalisation.

During the period when a policy of institutionalisation was in effect, the facility was known as the Saskatchewan Training School. It was planned that the Saskatchewan Training School would provide work and life skills training for people who had intellectual disability in the hope that they would be able to one day re-join the community. Later, when the Government of Saskatchewan turned to a policy of de-institutionalisation, the name of the facility was changed to the Valley View Centre and the facility began to adhere to contemporary care practices. When the Valley View Centre eventually closed in 2019, it had been in operation for approximately 65 years, and over 40 of these years were spent in a slow process of de-institutionalisation.

The Saskatchewan Training School was a modern structure that did not possess the Victorian era edifice that adorned many other institutional buildings. Instead, this institutional facility was designed in the modernist style that was rational in form and utility. Within its walls, and upon its grounds, the residents and employees of the Saskatchewan Training school would have their lives organised according to a prescribed set of standardised activities and

social rules. The low-rise wheat-coloured brick buildings were set back a kilometre or more from the highway, and while the Saskatchewan Training School could be seen from the City of Moose Jaw, it was situated apart from the city, across a river valley and upon a plateau.

The distance from Moose Jaw was intentional. The institutional facility was close enough to Moose Jaw to provide a source of employment and business opportunity, yet far enough way to maintain social distance between the institutionalised residents and the citizens of Moose Jaw. This social distance was thought necessary as institutional facilities were meant to care for vulnerable persons in an environment that is separate from the mainstream society. In the last years of the Valley View Centre, the bridge across the river was closed, forcing visitors and employees to take the long way around and enter the property through a back gate. Although the situation of the bridge was not intentional, it served as a symbol of the enduring social distance between the community and the institutionalised residents.

More than 60 years after it opened, the isolation of the site of the Saskatchewan Training School remains palpable, but that is neither unusual nor undesirable in rural Saskatchewan, which is known for long winters, flatter than flat grasslands, and long distances between homesteads. When people brought their children to the Saskatchewan Training School for the purpose of receiving care and education, the location was viewed as a serene and attractive environment where their loved one would be safe. For many people, the Saskatchewan Training School became the only home they had ever known. When the Saskatchewan Training School was re-branded in the 1970s to become the Valley View Centre, the residents largely remained the same, and there were many people that continued to reside at the facility for more than 50 years.

It is of the utmost importance to understand, that in 1955, the newly built institutional facility was thought to be the best home, in the best location, and it provided what was then believed to be the best care for people who have intellectual disabilities. While the opening of the Saskatchewan Training School was celebrated as a positive public policy achievement for the Government of Saskatchewan, and was widely admired, it is also true that admired public policies and best care practices tend to change. Therefore, this analysis of the birth and death of the Saskatchewan policy of institutionalisation for people who have intellectual disabilities must be viewed within the context that politicians, parents, medical practitioners, and other stakeholders were acting in accordance with what the medical community had then endorsed as the best form of care. Although the process of de-institutionalisation, at the societal level, has been a difficult and contentious project, there are no villains when it comes to the closure of the Moose Jaw facility. Now that a better form of care has been identified and developed, all contemporary stakeholders have agreed to embrace inclusivity and community care for people who have intellectual disabilities. Ultimately, this is because these contemporary stakeholders developed an ethic of person-centred care that supersedes all other related issues.

This dissertation describes how people may effectively work together to achieve policy change. While the details of how the Saskatchewan Training School came to be, how it evolved into the Valley View Centre, and how it came to close are the backdrop of what took place, the more significant story involves the work of the Valley View Centre Transition Steering Committee (VVCTSC), and why they succeeded when others have failed. Within the story are various narratives that concern how public policies come into being, and how these policies evolve into what is widely accepted as improved policies. These narratives concern the influence of competing ideologies upon evolving policy, both economic and social. It is also the

story of how individual actors come to change their minds about how things should be, and how they may effectively work with others, to not only improve policy, but to effect positive and lasting change in the lives of vulnerable people. Crucially, this dissertation is also the story of how to close an institutional facility the “right way”.

Within the current chapter, there is analysis of the origins of the Saskatchewan Training School, the evolving function of this institutional facility into the Valley View Centre, and the Government of Saskatchewan’s decision to permanently close Valley View Centre and transition the residents to community-based care. Included is a discussion of how de-institutionalisation in Saskatchewan was facilitated through a process of collaborative policy construction, which has been referred to as the ‘Made in Saskatchewan Approach’. Additionally, there are three substantive chapters that discuss the project of de-institutionalisation, both at the societal and local levels.

In Chapter Three, there is a broad analysis of institutionalisation in general, what it is, and how the international rise and fall of ‘Welfare State’ policies have impacted the architecture of care for people who have intellectual disability. These ideas lead to a theoretical explanation of de-institutionalisation as de-construction of the ‘Welfare State’, as well as how there has been a de-construction of care through policy neglect and policy drift. In Chapter Four, the focus turns to policy change and policy innovation in Saskatchewan, as these items relate to Saskatchewan’s long focus of attention toward the care of people who have intellectual disability.

Included in Chapter Four is a discussion of the role of certain policy entrepreneurs who have guided policy change within Saskatchewan. Although Saskatchewan has had several diverse Premiers through the period under study, the focus of this chapter remains on the few

policy entrepreneurs who worked assiduously to place policies of institutionalisation and de-institutionalisation on the government's agenda. Both motivation and opportunity are required to convince government to embark on a project as large and expensive as the closure of an institutional facility and the de-institutionalisation of long-time residents who have intellectual disabilities. Furthermore, this chapter reveals that Saskatchewan has pursued on a policy of institutionalisation for much of its history. Thus, when Progressive Conservative Premier Grant Devine's (1982-1991) privatisation agenda of the 1980s was implemented, the focus was on other economic sectors, particularly those with a more direct economic role. This policy drift continued until the election of Brad Wall of the Saskatchewan Party in 2007 who was highly motivated to deal with Saskatchewan's outdated policy of institutionalisation.

Chapter Five contains an overview of Saskatchewan's social movement for inclusion, and how relevant stakeholders overcame their differences, which allowed them to move forward to reach common goals. In Chapter Six, there is an examination of the process of permanently closing the Valley View Centre. This process of closure was a multi-year project that involved a social movement for de-institutionalisation in Saskatchewan that was achieved through the co-operative efforts of both the Saskatchewan Ministry of Social Services, Inclusion Saskatchewan, and the Valley View Centre Family Group, as well as other Stakeholders, and last, but certainly not least, the involvement of the residents of the Valley View Centre.

Beginnings:

In 1955, when institutionalised care was considered the best practice for vulnerable persons, the newly built facility was named the Saskatchewan Training School (STS). The Saskatchewan Training School had been a major component of the plan to innovate the delivery

of healthcare in Saskatchewan by the Co-operative Commonwealth Federation (CCF)¹ and Premier Tommy Douglas.² While ministering as a Baptist pastor to the residents of the Weyburn Mental Hospital during the 1930s, Tommy Douglas became motivated to transform the way in which people who have intellectual disabilities were cared for.³ Douglas held a personal interest in the welfare of vulnerable populations, and this interest has been attributed to his own battle with debilitating disease during his youth. Struggling with the effects of osteomyelitis, Douglas would have lost his leg if not for the intervention of a doctor that provided medical care for free.⁴ Additionally, Douglas was raised in a church that embraced the social gospel, which is rooted in a calling for social reform.⁵ After initially choosing a career as a clergyman, Douglas later focused on incorporating social gospel values into a successful political career that achieved a significant impact on Saskatchewan and Canada as a whole.

When it was opened in 1921, the function of the Weyburn Mental Hospital was to house and provide care for persons that were thought to be ‘mentally defective’. This defunct umbrella term included such people as those who have mental illness, intellectual disability, experience alcoholism or other addiction, or that did not conform to accepted social norms in moral behaviour. After he became the Premier of Saskatchewan, Tommy Douglas and the CCF developed policy to care for people who have intellectual disabilities separately from people who have mental illness, as this had become recognised by medical professionals as the best practice

¹ The CCF was a democratic-socialist political party founded in 1932 by various labour unions, socialist groups and farmer organisations, as well as the League for Social Reconstruction, which was a socialist think tank of academics and intellectuals. In 1961, the CCF had evolved to become the New Democratic Party of Canada. For a general history of the CCF see W.D. Young, *The Anatomy of a Party* (1969).

² Blaine Wickham, “Valley View Centre Heritage Report,” ed. Culture and Sport Ministry of Parks (University of Saskatchewan, 2012), <http://www.pcs.gov.sk.ca/VVC>.

³ Wickham.

⁴ Michael Shevell, “A Canadian Paradox: Tommy Douglas and Eugenics,” *Canadian Journal of Neurological Sciences* 39, no. 1 (2012): 35.

⁵ Shevell, “A Canadian Paradox: Tommy Douglas and Eugenics.”

in care.⁶ With an investment of 8 million dollars, 1.8 million of which was provided by the Federal Government of Canada, the Saskatchewan Training School came into being.⁷ The hope was that people who had intellectual disability could be trained to live and work within mainstream society.

The Saskatchewan Training School (STS) was specially designed to efficiently care for its residents.⁸ For example, there were underground tunnels so that residents and staff could safely pass between buildings without going outside into the harsh Saskatchewan climate. As well, the new institution contained a hospital with a paediatric ward, an operating room, X-ray facilities, dentistry facilities, and a pharmacy. The residents, or students as they were called, would benefit from training and occupational therapy by working in the kitchen, laundry, bakery, butcher shop or the irrigated garden.⁹ Additionally, there was a shoe shop, a clothing store, a barber shop, a hairdressing salon, a theatre, a school, and a swimming pool.¹⁰ The architect's goal was to create a facility that was not like a traditional institution, but instead like a small self-contained community.¹¹ This new and modern facility was self-sufficient, innovative, and the best standard in care recognised at the time.

The main innovation of the STS appears to have been the treatment of the residents as persons in need of education and life skills, rather than as persons in need of incarceration, as had been happening at the North Battleford Insane Asylum and the Weyburn Mental Hospital. This concept was evidently well received by the public considering that by 1957, just two years after opening, the Saskatchewan Training School was filled to capacity, and there were an

⁶ Wickham, "Valley View Centre Heritage Report."

⁷ Wickham.

⁸ Wickham.

⁹ Wickham.

¹⁰ Wickham.

¹¹ Wickham.

additional 500 applicants on a waiting list.¹² Clearly, the facility was viewed as a success and fulfilling the goals of the Provincial Government and the medical establishment. Anyone might have pointed to the Saskatchewan Training School as a crown jewel of achievement in the delivery of institutionalised care.

The widespread admiration of the Saskatchewan Training School was short-lived; however, as the facility began to suffer criticism as early as the 1960s with the start of a social movement for de-institutionalisation, and by the 1970s the government had already found it necessary to change the name of the facility to the Valley View Centre. Two related events served as a catalyst for the name change. The first was a 1968 newspaper editorial by Dr Lorne Elkin who was at that time the supervisor of psychological research at the Saskatchewan Training School. Elkin argued that the STS was failing at training residents and that those residents that were trained and ready to return to the community were not being accepted into the community.¹³ The second event was a 1973 article claiming that two residents had been held in the Saskatchewan Training School for many years after committing small misdemeanours as children, indicating that the STS was serving as a facility to house juvenile delinquents.¹⁴

These two events, however, were not the whole of the reason behind the change in focus that prompted a name change. When the STS was originally conceptualised, it was to serve physically capable people who have intellectual disabilities by teaching them marketable skills. The hope was that STS graduates would be prepared to enter the workforce and cope independently within society. As it turned out, however, by 1960 the STS had begun to admit

¹² Wickham.

¹³ Wickham.

¹⁴ Wickham.

long-term patients.¹⁵ Furthermore, by 1968 there were 125 residents who were deemed ready to leave the institution, but there was no place in the community for these people to live or work.¹⁶ Thus, the purpose of the STS had slowly shifted away from being an education program for people with developmental delay or intellectual disability, and into a long-term care facility for people with significant care needs, as well as a sort of juvenile hall for troubled youth. During this period, Saskatchewan people who have intellectual disability had few other care options except to enter the institutional facility.

When the STS opened its doors, philosophies about care delivery to people who have intellectual disabilities were already beginning to change. Instead of sending babies and children who had intellectual disabilities to live away from their families, the hope was that programs would be developed to help families care for their children at home. This sentiment was expressed by the provincial government in 1973 when then social services minister Alex Taylor announced that the former name of the institutional facility was no longer representative of the government's philosophy for delivering care.¹⁷ Additionally, that same year, the government produced a 164 page report that outlined the failures and inadequacies of the STS.¹⁸ Highlights of the report include how institutional care was considered obsolete, but also that STS suffered from over-crowding, staff shortages, and untrained staff.¹⁹ Despite the efforts and vision of Tommy Douglas and the CCF, the Saskatchewan Training School had developed similar problems to those that Douglas had witnessed in the Weyburn Mental Hospital.

¹⁵ Blaine Wickham, "Timeline of Significance for the Saskatchewan Training School (Valley View)," Government of Saskatchewan, 2010.

¹⁶ Wickham.

¹⁷ Wickham, "Valley View Centre Heritage Report."

¹⁸ Wickham.

¹⁹ Wickham.

Importantly, the Saskatchewan Training School was not performing its envisioned function, which was to improve living conditions and social outcomes for its residents. Despite every good intention, and great financial investment, the ‘state of the art’ model of institutional care for people who have intellectual disabilities had failed to meet expectations. By 1973, the Government of Saskatchewan embraced community-based care, hoping that families would be able to care for their own children at home in the manner that reflected research concerning de-institutionalisation and inclusion.²⁰ The name change of the STS to the Valley View Centre should be viewed as the beginning of the Government of Saskatchewan’s attempts to accept policies of de-institutionalisation and inclusion, rather than institutionalisation. Still, the Government of Saskatchewan neglected to create the necessary infrastructure within the community, and so the Valley View Centre remained in operation for several more decades before social and economic attitudes made closure of the institution possible.

De-institutionalisation cannot and will not occur over night, however. It is a decades long task that begins before governments decide to shut down an institutional facility, and the work of de-institutionalisation will persist long after an institutional facility finally closes.

The Decision to Close Valley View Centre:

Still in operation until 2019, the once ‘state of the art’ institutional facility had crumbled with age. This is by no means hyperbole. The structure of the facility was recognised by the Government of Saskatchewan to have been obsolete as early as 1973 and the depreciation of the property became clearly observable by the 2000s. As is the case for many buildings that are over 60 years old, the plumbing, wiring, and insulation no longer conformed to contemporary building codes. As well, the foundations had settled, and cracks appeared in the below-grade service

²⁰ Wickham, “Timeline of Significance for the Saskatchewan Training School (Valley View).”

corridors that connect the different buildings. A conservative estimate is that the Valley View Centre required 33 million dollars in necessary upgrades and renovations.²¹ Not only had the physical buildings deteriorated beyond the point of desirable use, but the Saskatchewan Ministry of Social Services did not wish to continue operating an institutional facility that did not conform to best practices in care. Purposely, no new residents had been admitted to the Valley View Centre in decades, and with an increasingly small population of residents, the logical move was to finally close Valley View Centre.

The Valley View Centre, which was built to house over 1000 people, had 230 residents in 2010.²² Institutionalised care in a facility such as the Valley View Centre once allowed governments to take advantage of savings through an economy of scale, but in the last decade or more, however, the Valley View Centre was subject to a dis-economy of scale. Costs per resident increased in a situation that was no longer considered the best form of care, or the least expensive. Added to the rising costs of care are the rising costs of building maintenance for an aged facility that no longer meets the building code, or the needs of current residents. In addition to the problem of rising costs is the substantial societal pressure to shut down large institutional facilities such as the Valley View Centre, and all over the world, institutional care facilities have already closed or are in the process of closing. For most stakeholders, it made both economic, moral and practical sense that Saskatchewan's Valley View Centre should also close.

This is not to say that the government of Saskatchewan chose to close Valley View Centre for purely economic reasons. In fact, most Stakeholder groups, including the Ministry of Social Services, demonstrated a desire to close the institution for the good of the remaining residents, rather than for any cost-saving measures that may have resulted. Any concern to

²¹ Personal conversation with Ministry of Social Services staff, 2014.

²² Wickham, "Timeline of Significance for the Saskatchewan Training School (Valley View)."

alleviate the dis-economy of scale associated with the Valley View Centre should be understood in the context that the funds recaptured from inefficient operations were reinvested into community-based care.

When the final decision to close Valley View Centre was put into action, most residents were senior citizens, and many had never known any other home. Before Valley View Centre could close, the Ministry of Social Services was required to make appropriate places available within the community. Keeping in mind that Valley View residents have always been free to leave the institutional facility if they chose to do so, they tended not to leave because community-living infrastructure was under-developed. The main barrier residents faced when leaving Valley View Centre was that they had nowhere else to go, and this barrier proved insurmountable for many residents. Transitioning the Valley View Centre residents to better forms of care in the community was difficult and costly, but the necessary expenses were not spared.

Institutions, De-institutionalisation, and the Economy:

While it has been recognised that community-living, rather than institutionalised care, produces better outcomes for vulnerable persons, part of the change in attitude is rooted in the shift in ideas regarding the role of the State as a provider of care. During the early 20th century, the dominant paradigm dictated a social policy of institutionalisation where those persons that were deemed physically or mentally incapable of full participation within the economy would be cared for by the State, sometimes through the services of religious organisations and voluntary groups, but very often by government employees. This social policy of institutionalisation was designed, not only to protect the welfare of vulnerable persons, but also to protect the larger society from the perceived moral deficiencies of these vulnerable persons. Current thinking no

longer subscribes to these notions about people who have intellectual disability and governments have been actively getting out of the business of institutionalised care over the last 50 years. The result has been the development and embrace of a policy of de-institutionalisation.

De-institutionalisation is a multi-faceted public policy challenge. There is no straightforward method of de-institutionalisation, and closing institutional facilities is only one part of the process. Included in this process is the de-institutionalisation of attitudes, the de-institutionalisation of persons, and the de-institutionalisation of the economic policies that facilitated the social policy of institutionalisation. It should be noted that in the case of the Saskatchewan Training School, the City of Moose Jaw campaigned to have the facility built in their community, and that by 1965, the STS was the 2nd largest industry in Moose Jaw with the Royal Canadian Air Force Station Moose Jaw having been the top employer of the time.²³

Institutional facilities have long served as an economic resource in Western liberal economies, and the de-institutionalisation of vulnerable persons has included a program of de-institutionalising the post-war welfare state. Therefore, beyond the issue of providing care to vulnerable persons differently, governments must carefully navigate through the collective agreements of labour unions, and deal with new economic structures such as public-private partnerships and their effect on labour. Institutionalisation permeates Western culture and it is necessary to ponder whether full de-institutionalisation is even possible, or if we should be spending more time conceptualising the social institutions that are on the rise. An institution is not simply a building or a method of care. Douglas North, for instance, refers to institutions as the constraints that are developed by humans in order to shape interaction.²⁴ There are reasons

²³ Wickham.

²⁴ Douglass North, *Institutions, Institutional Change and Economic Performance* (Cambridge: Cambridge University Press, 1990), 4.

why institutional care developed within Western liberal democracies, especially those nations descended from the British Empire, and it may be fair to say that institutional care developed organically.

Many facets of Western Civilisation have progressively bureaucratised over its history, growing its strength and efficiency through increasing forms of institutionalisation. Main examples are the Church, the factory, schools, prisons, hospitals—all institutionalised components of society that are organised in a similar manner, each highly bureaucratised based on maximising efficiency and economy of scale. The function of the institution is to maximise utility, to standardise, to control, and to organise. This management of institutional tools has become a science, which owes a debt to Frederick Taylor's 'Taylorism' and Henry Ford's 'Fordism', each well-known instruments of bureaucratisation that have served to rationalise human production. Scientific management continues to develop, and find favour, as is evidenced by programs such as 'LEAN' or 'Toyotism', which the Government of Saskatchewan chose to implement across all departments during the Wall government. With the advent of 'welfare markets', corporations now offer care services in institutional settings that depend on economy of scale to generate profit, which is a much different arrangement than the purpose of government run institutional facilities. Thus, there is a push-pull mechanism of institutionalisation and de-institutionalisation, with new institutions replacing abandoned ones.

The Government of Saskatchewan, on one hand is de-institutionalising some areas of its domain, while on the other hand is re-institutionalising others. They are dismantling old institutions such as the large-scale institutional care of persons with disabilities and building new institutions such as 'LEAN'. This helps us to understand that institutions are the building blocks of organisation and that it is not possible to simply close or end an institution. The void left by

the institution must be filled with something new or different. Within the case of the Valley View Centre, the void is being filled by community-based care.

De-institutionalisation through Collaborative Policy Construction:

In a move that is a unique ‘Made in Saskatchewan Approach’, the provincial government partnered with both the Inclusion Saskatchewan and the Valley View Centre Family Group (VVCFG) to close the Valley View Centre institutional facility. The government utilised the expertise of both Inclusion Saskatchewan, and the VVCFG, in order to ensure the development of appropriate community-based resources. Ultimately, the purpose of the ‘Made in Saskatchewan Approach’ is to mitigate the negative effects of transition from institutional to community living that have taken place within other jurisdictions. There is a substantial academic literature that describes the negative effects of transition from institutions to the community, which cover topics that range from inadequate investment in programs to the loss of employment for service providers, to the rationing of care services. From the point of view of the Government of Saskatchewan, the collaboration with stakeholders is meant to reduce the likelihood of implementing costly, but ineffective programs, and to avoid the problems faced by other governments that have attempted closure of a facility. Many other jurisdictions have been plagued by problems such as policy drift, cultures of neglect that are manifested in the reluctance of some governments to replace institutional forms of care, and various other pitfalls. Through the involvement of stakeholders, the government of Saskatchewan was able to pinpoint the specific needs of people transitioning into the community, ensuring family members and other advocates that the best decisions were being made.

The ‘Made in Saskatchewan Approach’ is an important experiment in collaborative public policy making. While many other jurisdictions have mostly dictated the terms of de-

institutionalisation to the stakeholders, the Government of Saskatchewan used an authentic citizen participation model that produced effective and efficient policy. To achieve authentic citizen participation, the Government of Saskatchewan accepted direction by care recipients, the VVCFG, and Inclusion Saskatchewan. The process of true collaborative policy construction was considered a risk, but it worked. Organisations that were traditionally at odds with one another came to mutually satisfactory decisions about how to close the Valley View Centre.

Despite the successful outcome, the closure of the Valley View Centre was not a simple task. Instead, the de-institutionalisation of the Valley View residents and the closure of the Valley View Centre was a complicated process that took many years to reach fruition. The Government of Saskatchewan publicly announced the closure in February of 2012, but it was impossible to complete the task before 2019. Originally, the final closure date was set for 2016, but this date was extended because there had not yet been sufficient time to ensure the community supports were in place. While there are instances of institutional closures taking place on a far more rapid timeline, in this case, the specific goals of both the Government of Saskatchewan, and all other stakeholders, were to ensure that the transitioned residents would move into a community that was equipped to provide them with adequate services. Creating the necessary infrastructure for community care is both difficult and time consuming, and therefore the timeline required adjustment. Still, the resolve of the Valley View Closure Steering Committee was firm, and they were determined to succeed in their ‘Made in Saskatchewan Approach’ to the transitioning of all residents into the community.

The aim of this dissertation is to learn from the Government of Saskatchewan’s successful experiment with collaborative policy construction, and to observe a model of citizen participation that is not only relevant to the closure of institutional facilities, but that could be

applied to a variety of other contentious projects. Many governments seem apprehensive about facilitating citizen participation that moves beyond mere tokenism. Yet, the closure of the Valley View Centre proves that a higher standard for democracy may emerge when trusting citizens to find workable solutions to pressing problems. The citizen participants that directed the Valley View Centre closure were average people whose connection to the project was simply that they had a family member or friend who has intellectual disability, and that were recognised advocates for people who have intellectual disability. Despite any fear that potential citizen participants may not be up to the task of a difficult project, the closure of the Valley View Centre demonstrates that even large and difficult projects may be successfully directed by citizens.

The people involved in the closure of the Valley View Centre are sincere, capable and were determined to see their task through for the greater good of all persons that have been or are currently institutionalised. Although de-institutionalisation is now the dominant policy in Canada and many other places, many attempts to close institutional facilities have suffered less than desired results. In the 'Made in Saskatchewan Approach' to de-institutionalisation, the government and other stakeholders were firmly fixated on the best individual needs of every resident of Valley View Centre; before, during and after their transition from the institutional facility to the community. This dedication to the needs of individuals and the values of inclusion are the foundation for the successful closure of the Valley View Centre.

Chapter 2

Methodology

The Grounded Theory Method in Producing Middle-Range Theory:

This research has taken the form of an exploratory case study that is focused on the events surrounding the closure of the Valley View Centre institutional facility. Using the constructivist version of the grounded theory method (GTM), which is an inductive method of drawing conclusions from data, the data is used to develop middle-range theory concerning the efficacy of citizen participation in public policy construction. The development of middle-range theory provides the ability to generalise conclusions from this case study and apply them to similar situations. In the case of the Valley View Centre, a significant public policy problem was alleviated through the utilisation of an authentic citizen participation model. This citizen participation model was unique and beyond the level of citizen involvement that is normally pursued within Saskatchewan or elsewhere. Lessons learned from this experience can enable positive outcomes for other difficult projects that governments must undertake. As a major goal of this research, theory generation about the processes of collaborative policy construction will benefit the public policy literature, and it will provide valuable insight to the Government of Saskatchewan and its collaborative partners.

Rather than using an existing theoretical framework to test the obtained data, grounded theory methodology has the intent of creating a new theoretical model that is derived from the data.²⁵ The grounded theory method is a widely utilised set of qualitative research methods that

²⁵ Phyllis Noerager Stern, "On Solid Ground: Essential Properties for Growing Grounded Theory," in *The Sage Handbook of Grounded Theory*, ed. Antony Bryant and Kathy Charmaz, Paperback (Thousand Oaks: Sage Publications, 2010). P. 114.

are systematic, inductive, and comparative.²⁶ The premise of grounded theory methodology is that new theory may be developed from the systematic collection and comparative analysis of data.²⁷ The newly generated theory is of the middle-range variety, meaning that the theories go beyond substantive description of ‘what is’, but still fall short of being an all-encompassing ‘grand’ or paradigmatic theory.

First conceived by Robert Merton, middle-range theorising is focused on limited categories of social phenomenon, such as the consequences of an action, how a certain social phenomenon is perceived, or how a particular social institution succeeds in exerting control.²⁸ For example, in the case of the Valley View Centre, grounded middle-range theorising is used to explain how divergent stakeholder groups came to forge a workable consensus. In turn, explanations of how the consensus building strategies succeeded for the Valley View stakeholders could inform other divergent stakeholder groups on how they could achieve consensus within their own projects.

Originally conceptualised by Barney Glaser and Anslem Strauss during the 1960s, GTM has developed into a widely used methodology with many diverse researchers adopting, adapting, and further developing the method.²⁹ Importantly, GTM endeavours to offer practical qualitative research methods that are appropriately rigorous.³⁰ The specific procedures of GTM include starting: “[w]ith individual cases, incidents, or experiences, and develop progressively more abstract conceptual categories to synthesize, to explain, and to understand your data and to

²⁶ Antony Bryant and Kathy Charmaz, *The Sage Handbook of Grounded Theory*, Paperback (London: Sage Publications, 2010). P. 1.

²⁷ Anselm Strauss and Juliet Corbin, “Grounded Theory Methodology,” in *Handbook of Qualitative Research*, ed. Norman Denzin and Yvonna Lincoln (Thousand Oaks: Sage Publications, 1994). P. 273.

²⁸ Robert K. Merton, *Social Theory and Social Structure* (New York City: The Free Press, 1968), file:///C:/Users/britt/Downloads/Merton, Social Theory and Social Structure.pdf. P. 51.

²⁹ Bryant and Charmaz, *Sage Handb. Grounded Theory*. P. 2.

³⁰ Kathy Charmaz, “Grounded Theory,” in *Approaches to Qualitative Research*, ed. Sharlene Negy Hesse-Biber and Patricia Leavy (Oxford: Oxford University Press, 2004). P. 496.

identify patterned relationships within it”.³¹ This goal is pursued through six main activities, which are: theoretical sampling rather than random sampling; analysing data as it is collected; developing concepts and categories from within the collected data; writing analytic memos about the data as it is collected; creation of middle-range theories that will explain behaviour and processes; and delaying the literature review until after collected data is analysed.³² These activities are performed simultaneously and involve constant comparative analysis where emergent theory is constantly weighed against the collected data.³³ Each of the individual methods have their own function, but used together they serve the researcher’s attempt to seek new information.

Since any conclusions arise from within the collected data, the grounded theory method aims to relieve the researcher of the restrictive burden of any specific methodological paradigm.³⁴ Thus, the case of the Valley View Centre is purposely not filtered through any pre-determined political or theoretical lens with the intention that researcher bias will be kept to a minimum. Instead of collecting data that is sure to complement extant theories, the goal is to develop new ideas that concern the phenomenon under study. Therefore, the goal of GTM is not to merely replicate and confirm extant theories, but rather, to improve upon those theories or develop new theories. GTM has been described as providing: “[a] sense of vision of where it is that the analyst wants to go with the research”.³⁵ In conducting an exploratory case study using GTM, the researcher may develop theory: “[t]hrough directly observing some social

³¹ Charmaz. P. 497.

³² Charmaz. P. 497.

³³ Strauss and Corbin, “Grounded Theory Methodology.” P. 273.

³⁴ Anselm Strauss and Juliet Corbin, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (Thousand Oaks: Sage Publications, 1998).

³⁵ Strauss and Corbin. P. 8.

phenomenon in its natural and raw form”.³⁶ Ultimately, therefore, the goal of studying the case of the Valley View Centre is to determine what lessons could be derived from the de-institutionalisation of Valley View residents and the closure of the institutional facility itself.

Despite the focus on middle-range theorising, grounded theory studies can generate both substantive theories and higher-level theories.³⁷ Still, it is important to understand that any higher-level theories that might be advanced must be inductively derived, meaning that the theories are always linked to the collected data.³⁸ Notably, middle-range theories may become the building-blocks of inductively derived higher-order formal theory.³⁹ Two examples of attempts at grounded formal theory is the work by Glaser and Strauss on status passages, and Strauss’s theory of negotiation.⁴⁰

The grounded theorist is on a quest to seek patterns of action and interaction between individuals and groups.⁴¹ Thus, in the case of the Valley View Centre, the goal is to discover how the various stakeholders interacted with each other, and how these interactions influenced the outcome of the de-institutionalisation project. Through the observation of actions and their consequences, the researcher may determine which sort of actions are likely to lead to specific outcomes. In this manner, the grounded theories become: “[s]ystematic statements of plausible relationships”.⁴² At the same time, theories are not static, and are dependent upon time and place, which means that as more data is collected and analysed, assumptions about the data are apt to evolve.

³⁶ Bruce Berg, *Qualitative Research Methods for the Social Sciences*, 7th ed. (Boston: Pearson, 2009). P. 327.

³⁷ Strauss and Corbin, “Grounded Theory Methodology.” P. 274.

³⁸ Strauss and Corbin. P. 276.

³⁹ Anselm Strauss and Barney Glaser, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Chicago: Aldine, 1967).

⁴⁰ Strauss and Corbin, “Grounded Theory Methodology.” P. 282.

⁴¹ Strauss and Corbin. P. 276-278

⁴² Strauss and Corbin. P. 278.

Actors are bounded by their locations within specific societies and the constructed realities of their societies.⁴³ Therefore, when societal circumstances change, patterns of action will also be apt to change. Thus: “[t]heories are embedded in history—historical epochs, eras, and moments are to be taken into account in the creation, judgement, revision, and reformulation of theories”.⁴⁴ For this reason, the case study of the Valley View Centre is necessarily situated within the historical and social context of public policies of institutionalisation and economic organisation descended from the British Empire, the history of Saskatchewan in social and political context, and economic ideologies regarding both the construction and de-construction of ‘welfare states’. To understand how the Government of Saskatchewan was obligated to deal with the difficult task of de-institutionalisation and the closure of the Valley View Centre, it is important to first understand why the institutional facility had existed in the first place. Thus, this case study of the Valley View Centre includes exploration of: a general history of institutionalisation in the context of the British Empire; the history of Saskatchewan policies for people who have intellectual disability; a general history of the international social movement for de-institutionalisation; an overview of the social movement for inclusion within Saskatchewan, and the development and dismantling of ‘welfare states’ in historical context. The idea to construct each of these histories arose out of the data during collection and analysis.

The Valley View Centre Transition Steering Committee as a Research Site:

The research site was the collaborative process of the Valley View Centre Transition Steering Committee (VVCTSC), where diverse stakeholders put aside their differences and realised their common goals. A collaborative process is not a physical location, but an activity. Thus, the bulk of the data were drawn from the activity of collaboration, and its products, which

⁴³ Herbert Simon, *Models of Man: Social and Rational* (New York City: John Wiley & Sons, 1957).

⁴⁴ Strauss and Corbin, “Grounded Theory Methodology.” P. 280.

include deliberations, strategic planning, and the joint construction of recommendations and policy. Although the case was confined to the collaborative partnership between the Government of Saskatchewan, Inclusion Saskatchewan (INSK), and the Valley View Centre Family Group (VVCFG), which was created solely for the purpose of the transition from institutionalised to community-based care for the Valley View residents, other forms of data were collected. This additional data included archived historical documents produced by the stakeholders, newspaper articles, and academic literature concerning institutionalisation, de-institutionalisation, and citizen participation in policy construction.

There is an argument that social science must include theoretical use of historical information,⁴⁵ and this case study of the Valley View Centre applies this maxim. To this end, a historical point of view was applied, and this point of view was constructed through the primary analysis of various documents and other media produced by the stakeholders. As well, secondary sources of historical information from both sociological and historical literature were consulted. Importantly, it is recognised that historical points of view are dependent upon the researcher's subjective interpretation of data sources.⁴⁶ In keeping with grounded theory methodology, however, the researcher constructed the historical framework of the case study based on recurring themes within the collected data.

Practical Methods:

Data was collected from three main sources. These sources were documents and other media produced by the stakeholders, direct observation of the stakeholders, and open-ended interviews with citizen participants. The first of these, documents and other media, consisted of

⁴⁵ Gaye Tuchman, "Historical Social Science," in *Handbook of Qualitative Research*, ed. Norman Denzin and Yvonne Lincoln (Thousand Oaks: Sage Publications, 1994). P. 306.

⁴⁶ Tuchman. P. 315.

official memos, minutes, records, videos, reports, promotional materials and archival materials that were produced by the relevant stakeholders. The intent of analysing these items is to observe narratives and themes that exist within the written materials produced within the research site.⁴⁷ Collection of this form of data allows the researcher to observe the process by which the collaborative policy construction takes place, as well as to isolate important themes and discourses embraced by the research participants. The data also revealed which ideas about de-institutionalisation, inclusivity and community care are important to the research participants.

The second data source, direct observation, involved observing meetings of VVCTSC that were part of the process of collaborative policy construction. Direct observation requires a non-participant role, which means the researcher does not participate in, or influence the meetings in any manner. Data gathered was limited to how the meetings are structured, how they are administrated, and how the research participants make decisions and achieve consensus. Physical data gathering took the form of written note taking by the researcher. This form of data collection serves to illustrate which themes and ideas are important to the research participants, and that reveal effective practices and administration of the collaborative policy construction process.

The third source of data came from open-ended interviews with the citizen participants. In the interests of theory generation, interviews were unstructured. Research participants were asked open-ended questions about their participation in the collaborative policy construction process. In conformity with grounded theory methodology, the interview questions arose out of the data collected, and were focused on the unfolding process of collaborative policy

⁴⁷ John Cresswell, *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*, Second (Thousand Oaks: Sage Publications, 2007). P. 54.

construction.⁴⁸ Analytical coding of the data took place during the process of collection, enabling the researcher to identify themes and discourses that are of importance to the research participants. Since the goal of this research is to form middle-range theories about collaborative policy construction, the researcher must engage in the process of open, axial and selective coding of the emerging data.⁴⁹

This triangulation of data collection facilitated the development of a theory of collaborative policy construction by allowing the researcher to obtain similar or identical information from multiple sources. Such a technique enhances validity as it assures the researcher that any: "[v]ariance reflected is that of the trait of treatment and not that associated with the measures".⁵⁰ Multiple methods of data collection are necessary as this technique improves the quality and depth of the generated theory.⁵¹ For example, the interviewed citizen participant stakeholders would frequently repeat phrases that were also available in published documents and other media. This allowed the researcher to construct a set of concepts about de-institutionalisation and inclusion for further analysis. Data triangulation has long been recognised as an essential tool in the pursuit of grounded theory as the researcher attempts to:

self-consciously set out to collect and double-check findings, using multiple sources and modes of evidence, the researcher will build the triangulation process into ongoing data collection. It will be the way he or she got to the finding in the first place—by seeing or hearing multiple instances of it from multiple sources, using different methods, and by squaring the findings with others with which it should coincide.⁵²

⁴⁸ Cresswell. P. 66-67.

⁴⁹ Cresswell. P. 67.

⁵⁰ A. Michael Huberman and Mathew Miles, "Data Management and Analysis Methods," in *Handbook of Qualitative Research*, ed. Norman Denzin and Yvonne Lincoln (Thousand Oaks: Sage Publications, 1994). P. 438.

⁵¹ Berg, *Qualitative Research Methods for the Social Sciences*. P. 6.

⁵² Huberman and Miles, "Data Management and Analysis Methods."

The research design, which remained fluid throughout the study, was developed using the six methods identified above. The reasoning behind a fluid research design is to avoid searching for pre-conceived hypotheses. When data collection began, it was only with the understanding that the Government of Saskatchewan was hoping to close the Valley View Centre using citizen participation, and that this was something that had rarely been done before, if ever. Additionally, the research site, the potential research participants, disability policy, the institutionalisation of people who have intellectual disability, the closure of institutional facilities, de-institutionalisation, and the use of citizen participation in constructing policy, were all people and concepts unknown to the researcher. At the outset, there was no indication that the Government of Saskatchewan's project to close the Valley View Centre would be a success, and likewise, the researcher had not yet conceptualised what a successful closure of an institutional facility meant. Thus, when the researcher entered the field, it was without any pre-conceived agenda, which is considered an advantage for grounded theory generation. When the researcher is initially unfamiliar with the research site, the key issues can emerge from the collected data instead of emerging from pre-existing literatures and concepts.⁵³

Theoretical sampling refers to two main practices. The first task is determining who the research participants will be. In the case of the Valley View Centre, the potential research participants were drawn from the groups of stakeholders that were directly involved in planning the transition process. In this regard, theoretical sampling refers to non-probability, purposive sampling of the bureaucrats, INSK and VVCFG members associated with the closure of the Valley View Centre. Both case studies and grounded theory studies demand that a sample be drawn from within the event, activity or program being studied.⁵⁴ In this case, the targeted

⁵³ Charmaz, "Grounded Theory." P. 516.

⁵⁴ Cresswell, *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. P. 119-123.

research participants were actively involved in the collaborative policy construction process and had specialised knowledge concerning the topics of de-institutionalisation and community-based care.

The second task of theoretical sampling involves the selection of specific participants and the coding of collected data. After initial data is obtained and analysed, decisions are then made concerning which research participants and topics should be pursued. From the initial data, emerging issues will assist the researcher to construct analytical categories that may be used to build theory.⁵⁵ This cycle of collecting data, analysing the data, and targeting new research participants or sources, should continue until the data becomes saturated.⁵⁶ The data becomes saturated once data collection becomes repetitive and without the emergence of new concepts. In the case of the Valley View Centre, data was collected between 2014 and 2019, but it was apparent by 2016 that new concepts were no longer emerging.

Analysis during data collection is a necessary component within the grounded theory approach that enables the researcher to develop categories and the relationship between these categories.⁵⁷ To construct these initial categories, the researcher will use a line by line microanalysis of the collected data.⁵⁸ As the collected data is coded, the researcher will look for common words, phrases, themes, or references to specific people or ideas.⁵⁹ In the case of the Valley View Centre, there were many items in common across the data obtained through direct observation and interviewing of the stakeholders. For example, there was the phrase: “[p]eople

⁵⁵ Charmaz, “Grounded Theory.” P. 514.

⁵⁶ Charmaz. P. 515.

⁵⁷ Strauss and Corbin, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. P. 57.

⁵⁸ Strauss and Corbin.

⁵⁹ Berg, *Qualitative Research Methods for the Social Sciences*. P. 348.

who have intellectual disability”.⁶⁰ It was never ‘intellectually disabled people’, or ‘people who suffer from disability’, or ‘people with a developmental disorder’ as was seen in the other data sources such as the academic literature, news reports and other media.

Although it was readily apparent that the development of an argot that was tied to time and place would be shared by advocates of de-institutionalisation and inclusion, this was only the surface of the meaning behind the preferred phrasing. In the pursuit of meaning, the researcher soon discovered that the preferred phrasing differed based on location, and social movements for de-institutionalisation in Canada, the United States, and Britain each developing their own point of view on how to describe the people they advocate for. By paying attention to specific uses of terminology, it was possible to ascertain the location in time and place of the advocate, how immersed in the social movements for de-institutionalisation and inclusion the advocates were, or even if they were true advocates at all.

The brief discourse analysis in the above example is useful to the researcher as it illustrates how social actors construct their view of the social world.⁶¹ In Canada, as the social movement for inclusion developed, the notion of ‘people first’ became a dominant theme as it has become desirable to eschew the notion that intellectual disability is related to being ‘defective’ or ‘disordered’. The words used to describe people who have intellectual disability have transformed from phrases such as ‘the mentally defective’ to ‘the mentally retarded’ to ‘the mentally disabled’ and many other phrases until the contemporarily preferred phrase of ‘people who have intellectual disability’ was adopted—which has significant meaning to the stakeholders that, above all else, they are advocating for people. The reason why there has been such an evolution of preferred phrasing can be attributed to changes within social attitudes. As

⁶⁰ The Stakeholders, “Interview Data” (Saskatoon, n.d.).

⁶¹ Berg, *Qualitative Research Methods for the Social Sciences*. P. 353.

the social movement for inclusion evolves further, it is possible that a new description will eventually be inter-subjectively constructed by advocates for inclusion.

Attention to the argot of research participants is especially helpful for the analysis of public policies and how they are constructed by policy actors. Policy issues are defined within the frameworks constructed by policy actors and the resulting policies are influenced by the meanings that are attributed to them. For instance, the evolution of names from the Saskatchewan Training School, to the Valley View Centre, to Community Living Service Delivery are all manifestations of how policy actors have defined people who have intellectual disability over time.

As the researcher analyses the data to develop categories, they should also engage in memo-writing. During analysis, the researcher records any ideas or themes that come to mind.⁶² This memo becomes a map of concepts and relationships between the concepts that the researcher may pursue. For example, in the case of the Valley View Centre, the researcher questioned herself why Saskatchewan had built such a large institutional facility in the first place, and why old newspaper reports discussed aggressive competition between Saskatchewan communities to be able to host the planned facility. The researcher was then able to compare memos that outlined these questions with memos that described recurring complaints from stakeholders that some opponents to the closure of the Valley View Centre were too focused on economic issues. Seeking the relationship between the two memos, the researcher was compelled to begin collecting data on the relationship between policies of institutionalisation and Saskatchewan's economy.

⁶² Berg.

Research concerning the history of Saskatchewan and its economic reliance on institutionalisation led to the researcher's creation of middle-range theory concerning how Saskatchewan relied on policies of institutionalisation, and why Saskatchewan was slower than other jurisdictions in pursuing de-institutionalisation. As well, it became possible to compare the history of institutionalisation policies in Saskatchewan with the more general history of institutionalisation policies in Britain and the British Empire, a road that may not have been taken if not for the constant method of theoretical sampling of topics that arose from the collected data.

In addition, memos that outlined the economic issues complemented memos written about the barriers to de-institutionalisation that were faced by the stakeholders. This led to middle-range theory concerning how the Valley View Centre Transition Steering Committee and the Government of Saskatchewan were able to avoid the situations that served to de-rail de-institutionalisation projects within other provinces—not the least of which was organised opposition from labour unions.

One of the most important aspects of the grounded theory method is that literature review is delayed until after significant data collection and analysis has commenced. In the case of the Valley View Centre, there were several returns to the academic literature as new concepts arose. In the first stage, after some initial data was collected about the plans to de-institutionalise the Valley View Centre, a general literature review was conducted on de-institutionalisation. This literature review provided the researcher with information about what de-institutionalisation was, how it has been conducted in other jurisdictions, and why governments have been compelled to close institutional facilities. Ultimately, this literature review mirrored many of the activities that had been undertaken by the Government of Saskatchewan such as a re-structuring of the

economy that included the development of ‘welfare markets’, rather than state provision of welfare.

Later, after it had become clear by 2016 that the closure of the Valley View Centre would proceed and that all relevant stakeholders were pleased with the outcomes, another literature review was performed. This time, the literature review concentrated on theoretical models of citizen participation. The form and features of the unique ‘made in Saskatchewan’ model of citizen participation used to facilitate the closure of the Valley View Centre were then compared to some dominant citizen participation models that exist within the literature.

These six methods were performed simultaneously, and the researcher is confident that the constant comparison of source materials has led to useful middle-range theories that provide a general pathway for social advocacy groups to achieve goals through the collaborative construction of public policy. Additionally, the researcher believes that it is possible to use the theories generated here as building blocks for a more formal theory regarding institutional change.

Ethical Considerations:

The University of Saskatchewan’s Behavioural Research Ethics Board determined that this research project was exempt from oversight. A copy of this decision is located within

Appendix I, which states the project is:

deemed exempt as per Article 2.1 of the Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans, December 2010 that specifies “research may involve interaction with individuals who are not themselves the focus of the research in order to obtain information. Such individuals are not considered participants for the purposes of this Policy. This is distinct from situations where individuals are considered participants because they are themselves the focus of the research”.

Despite exemption from requiring oversight from an ethics board, this study nevertheless conforms to the University of Saskatchewan's standards for ethical research and seeks to limit any potential harms to the research participants. The research participants were provided with a 'Participation Information Sheet', which is located within Appendix II. The participation information sheet notifies the participant that research is being conducted, and that participation is voluntary. Notably, permission was granted by Community Living Service Delivery for the researcher to conduct the research, interview relevant participants, and to attend the VVCTSC meetings.

As the closure of the VVC and the transition of the Valley View residents into the community is a government project conducted in the public square, it is not possible or desirable to guarantee full confidentiality. The identity of the members of the VVCTSC are, as well as their achievement, a matter of public record. Therefore, some of the dissertation text will identify VVCTSC members and some of their statements will be attributed to them personally. Most statements made by VVCTSC members will NOT be attributed to a specific committee member, but instead attributed to "a stakeholder" or a "committee member", or an "inclusion advocate".

The closure of the Valley View Centre has attracted public interest and media scrutiny. For this reason, additional care must be taken in order to ensure anonymity of the research participants when warranted. Therefore, three levels of confidentiality were applied to the data. These are:

- **Level 1 (statements that are attributed to a participant):** applied to publicly available information and information that positively enhances an understanding of the VVCTSC members
 - Identity of VVCTSC members
 - Statements that VVCTSC members made to the media
 - Statements that were made in one's capacity as a VVCTSC member

- Example: “Inclusive education is very important to me”
 - Statements regarding a VVCTSC member’s motivations and life experiences
 - Example: “I got involved because my family member lived at VVC” or “I want to make sure things are done right”.
- **Level 2 (statements that are attributed to an undisclosed participant):** applied to information that is not publicly available, but that shed a useful light on the process of collaboration
 - Statements concerning problem solving
 - Example: “There are always some struggles in the beginning”
 - Statements about the closure of other institutional facilities
 - Example: “What happened at Michener was a disaster”
 - Statements regarding political issues about de-institutionalisation
 - Example: “some stakeholders had indicated that the tendency of People First activists to compare life at the Valley View Centre to living in a Nazi concentration camp was hurtful and inaccurate”.
- **Level 3 (sensitive data resulting from direct observation or interviews are effectively obscured):** applied to information derived from confidential sources
 - Data obtained from meeting minutes
 - Example: any identifying information about Valley View residents and family members is not disclosed. If a transition problem is discussed, it will only be in the vaguest sense and impossible for outsiders to identify the situation that occurred. The only purpose of mentioning transition problems is to illustrate how the VVCTSC dealt with problems. The text might read as: “a family member telephoned VVCFG very worried about their loved one adjusting to their new home. After being brought to the attention of the VVCTSC, the situation was investigated immediately by MSS and appropriate changes were made and the issue resolved”
 - Data obtained from ‘jotted notes’
 - Example: anything that I wrote down during meetings will not disclose personal or confidential information.
 - Data obtained from someone providing unsolicited information
 - Example: “one inclusion advocate remarked that they really respected Eugene’s efforts”.
 - Sensitive data obtained during an Interview:
 - Example: information concerning a participant’s child’s identity or condition is not revealed.

With the consent of research participants, all interviews were digitally recorded, and then transcribed by the researcher. The researcher was the only person to hear the recorded interviews, and after transcription was completed, the digital recordings were destroyed. To ensure that the research participants' experiences and attitudes were appropriately represented, the VVCTSC members were given the opportunity to verify the authenticity of the chapters that pertained to them. This meant that chapters 5 and 6 were distributed to the VVCTSC for their approval. A copy of a satisfaction checklist is available in Appendix III.

Some research participants requested minor changes to the text, and these changes were happily completed by the researcher. The changes requested were limited to issues of classification or the 'softening' of a statement that the participant later regretted as too harsh. For example, the researcher had referred to 'de-institutionalisation activists' in various places within the text. The research participants communicated to the researcher that they believed 'de-institutionalisation advocates' was a preferred phrase. The reasoning behind this requested change was because of a perceived belief that the term 'activist' sounded negative and associated with protesting and trouble-making, while 'advocates' was a positive term perceived to be associated with helping people. Therefore, throughout the text there is reference to 'advocates of deinstitutionalisation' and 'inclusion advocates'. After consultation with the research participants, the researcher is confident that the text accurately portrays the actions and attitudes of the research participants.

Reflexivity and Positionality:

It is improbable for any research to be performed without bias, and this problem has long been recognised within the philosophy of science. Despite this, the *methodenstreit* continues with grounded theory methodology often serving as a tool in the continued quest of some

researchers to present subjective work as objective. Some of these efforts are functional in that the researcher must often satisfy the demands of their empirically minded supervisors and peers. At the same time, those who venerate empirical data must increasingly offer something of substance to their colleagues who embrace reflexive styles of ethnography. Although grounded theory is sometimes believed to provide a framework to objectively analyse qualitative materials, the methodological problems remain unresolved.

In regard to the study of human group life, the 20th Century form of the philosophy of science recognised three main paradigms which are ‘positivism’, ‘realism’, and ‘conventionalism’.⁶³ Positivists assert that the study of phenomena must be oriented toward the universal laws of scientific theory.⁶⁴ As such, the positivist social scientist seeks to find evidence of replication within human action. The realist also maintains an interest in empirically based objective results, but the focus is on explanation of phenomena.⁶⁵ Thus, the realist social scientist is searching for the reasons why phenomena occur and believe they may do so in an empirical and objective manner. The conventionalists diverge from the positivist and realist paradigms by rejecting empiricism in social science.⁶⁶ Specifically, the conventional social scientist tends to believe that: “[i]n order to derive testable consequences from a theory, it is usually necessary to make assumptions additional to those involved in the theory itself”.⁶⁷ As well, the conventionalist will argue that people interpret what they observe differently, and that their observations are influenced by existing theories. A famous example concisely describes how theories determine interpretation:

⁶³ Russel Keat and John Urry, *Social Theory as Science* (London: Routledge and Kegan Paul Ltd., 1975). P. 4.

⁶⁴ Keat and Urry. P. 4-5.

⁶⁵ Keat and Urry. P. 5.

⁶⁶ Keat and Urry. P. 45.

⁶⁷ Keat and Urry. P. 47.

Let us consider Johannes Kepler: imagine him on a hill watching the dawn. With him is Tycho Brahe, Kepler regarded the sun as fixed: it was the earth that moved. But Tycho followed Ptolemy and Aristotle in this much at least: the earth was fixed, and all other celestial bodies moved around it. Do Kepler and Tycho see the same thing in the east at Dawn?⁶⁸

The conventionalist tends to answer yes, that the two scientists saw the same thing, but interpreted the phenomenon very differently. It was their acceptance of differing, but widely disseminated scientific theories that led to the difference in interpretation, and not the physical act of observing the same sunrise. Ultimately, the results of scientific experiments are theory-laden and will assume personal beliefs and scientific theories as facts.⁶⁹ Policy analysts would be wise to take note of this issue, in particular, as many contemporary qualitative researchers assert that public policies are created based on how the issues are defined and who defines them.⁷⁰ Considering how many of the early heliocentrist astronomers found themselves in serious legal trouble, it becomes possible to easily observe how policies can be constructed within the confines of a belief system.

The conventionalist point of view is further explicated by Thomas Kuhn in his “The Structure of Scientific Revolutions”. Within this critical statement on the scientific method, Kuhn asserts that:

no natural history can be interpreted in the absence of at least some implicit body of intertwined theoretical and methodological belief that permits selection, evaluation and criticism. If that body of belief is not already implicit in the collection of facts—in which case more than “mere facts” are at hand—it must be externally supplied, perhaps by a current metaphysic, by another science, or by personal or historical accident. No wonder, then, that in the development of any science different men

⁶⁸ Keat and Urry. P. 50.

⁶⁹ Keat and Urry.

⁷⁰ Virginia Oleson, “Feminisms and Models of Qualitative Research,” in *Handbook of Qualitative Research*, ed. Norman Denzin and Yvonne Lincoln (Thousand Oaks: Sage Publications, 1994).

confronting the same range of phenomena, but not usually all the same particular phenomena, describe and interpret them in different ways.⁷¹

Thus, even the production of the hardest of ‘hard science’ is beholden to the subjective inferences of the researcher’s individual mind. An issue germane to the topic of human rights for people who have intellectual disability relates to the attitudes of Richard Dawkins toward people who have Down Syndrome. Dawkins has made it his life’s work to promote science, secularism, and to reduce the influence that religion has on education and public policy.⁷² Notably, Dawkins and his foundation assert that failing to have an: “[e]vidence-based view of the natural world” will have negative consequences.⁷³ Therefore, when Dawkins cultivates ideas, his followers tend to assume that he does so on the basis that these ideas are grounded in scientific fact rather than on personal value-judgements. In 2014, however, Dawkins used a social media account to state that it was immoral to give birth to a child with Down Syndrome—with the insistence that his determination was based on a scientific application of logic, ethics, and facts. Dawkins’s original statement was a reply to a woman who wondered what she should do now that her unborn child had been diagnosed with Down Syndrome. Dawkins advised her to: “[a]bort it and try again. It would be immoral to bring it into the world if you have the choice”.⁷⁴ Unsurprisingly, Dawkins’s statement elicited strongly negative reactions from diverse individuals and groups that included advocates for inclusion, parents of children who have intellectual disability, pro-life advocates, and bioethicists.

⁷¹ Thomas Kuhn, *The Structure of Scientific Revolutions*, Third (Chicago: University of Chicago Press, 1962). P. 17.

⁷² Richard Dawkins, “Richard Dawkins Foundation for Reason & Science,” Richarddawkins.net, 2019, <https://www.richarddawkins.net/aboutus/>.

⁷³ Richard Dawkins.

⁷⁴ Press Association, “Richard Dawkins Apologises for Causing Storm with Down’s Syndrome Tweet,” *The Guardian.Com*, August 21, 2014, <https://www.theguardian.com/science/2014/aug/21/richard-dawkins-apologises-downs-syndrome-tweet>.

The Down Syndrome Association was particularly alarmed at what they perceived as a threat to the legacy of their advocacy work in raising positive awareness about Down Syndrome, stating: “[p]eople with Down’s Syndrome can and do live full and rewarding lives, they also make a valuable contribution to our society”. Undeterred and compelled to defend his position, Dawkins doubled-down on his assertion and published a longer treatment of the issue on his website, explaining that this is what he would have responded to the woman’s question if he had the space to do so:

Obviously, the choice would be yours. For what it’s worth, my own choice would be to abort the Down foetus and, assuming you want a baby at all, try again. Given a free choice of having an early abortion or deliberately bringing a Down child into the world, I think the moral and sensible choice would be to abort. And, indeed, that is what the great majority of women, in America and especially in Europe, actually do. I personally would go further and say that if your morality is based, as mine is, on a desire to increase the sum of happiness and reduce suffering, the decision to deliberately give birth to a Down baby, when you have the choice to abort it early in the pregnancy, might actually be immoral from the point of view of the child’s own welfare. I agree that that personal opinion is contentious and needs to be argued further possibly to be withdrawn. In any case, you would probably be condemning yourself as a mother (or yourselves as a couple) to a lifetime of caring for an adult with the needs of a child. Your child would probably have a short life expectancy but, if she did outlive you, you would have the worry of who would care for her after you are gone. No wonder most people choose abortion when offered the choice. Having said that, the choice would be entirely yours and I would never dream of trying to impose my views on you or anyone else.⁷⁵

Note that Dawkins uses words such as ‘moral’ and ‘sensible’ and asserts that morality is based on ‘increasing happiness’ and ‘reducing suffering’. These are value-judgements as opposed to scientific fact, but Dawkins has written up these value-judgements as though they were opinions derived from scientific fact. Furthermore, Dawkins chides some of his critics by claiming that: “[t]hose who took offence because they know and love a person with Down

⁷⁵ Richard Dawkins, “Richard Dawkins Foundation for Reason & Science.”

Syndrome, and who thought I was saying that their loved one had no right to exist, I have sympathy for this emotional point, but it is an emotional one not a logical one”.⁷⁶ Such a statement indicates that Dawkins quantifies the value of moral standpoints, —with those standpoints that he believes to be based in logic being superior.

Dawkins also provoked the ire of bioethicists, one of whom sharply rebuked Dawkins and suggested that he would fail a basic philosophy course.⁷⁷ Her reasoning involved Dawkins’s apparent attempt to apply the moral philosophy of ‘act-utilitarianism’ and measure the quantity of happiness or suffering caused by the birth of a baby who has Down Syndrome.⁷⁸ Dawkins, apparently, asserted that choosing to give birth to such a child is immoral because it causes too much suffering. Of course, there are no reliable measures to determine how much suffering is too much, or how much happiness is not enough. The author of the rebuke wonders if Dawkins is claiming that: “[a]n action is immoral when it makes the entire world worse off. If that is true, and he has stated he thinks it’s immoral knowingly to give birth to someone with Down Syndrome, does he think the mere presence of people with Down Syndrome increases suffering in the world?”⁷⁹ University of Toronto Lecturer Paul Raymont agreed that Dawkins’s sentiments are troubling, stating that:

For Dawkins to publicly recommend doing this and to say that the alternative is immoral, is for him to send a very clear message about existing people who have Down Syndrome—he’s saying they are morally inferior to the rest of us and that future generations would be much better off without their kind. He may not have intended to send that message, but he has done so (whether he knows it or not). He has also, whether he

⁷⁶ Richard Dawkins, “Abortion and Down Syndrome: An Apology For Letting Slip The Dogs Of Twitterwar,” Richarddawkins.net, 2014, <https://www.richarddawkins.net/2014/08/abortion-down-syndrome-an-apology-for-letting-slip-the-dogs-of-twitterwar/>.

⁷⁷ Elizabeth Picciuto, “Richard Dawkins Would Fail Philosophy 101,” *The Daily Beast*, 2014, <https://www.thedailybeast.com/richard-dawkins-would-fail-philosophy-101?ref=scroll>.

⁷⁸ Picciuto.

⁷⁹ Picciuto.

knows it or not, expressed moral disapproval of parents who had prenatal tests but decided to go ahead and have the Down syndrome baby.⁸⁰

This situation with Dawkins and his acceptance of act-utilitarianism to measure morality demonstrates that scientific viewpoints are vulnerable to the creeping influence of value-judgements. Scientific attempts to quantify the unquantifiable or judge what constitutes the greatest good tends to fail. There are countless examples of scientists pursuing what they believe to be the greater good, and yet these examples have often involved the persecution of vulnerable populations. As is argued within this dissertation, policies of institutionalisation that have led to segregated and custodial care of people who have intellectual disability is a prime example of how scientific attitudes are influenced by ideologies.

Despite recognition that value-judgements influence research, many methodologies continue to struggle to overcome the problem, contributing a great deal to the proliferation of disciplines and paradigmatic schisms. In the 19th Century, social science was influenced by ideas from natural science, particularly Darwinism.⁸¹ Max Weber famously critiqued the trend toward Darwinism and explored the role of values in science. In his 1917 essay entitled “The Meaning of Ethical Neutrality”, Weber asserted that some value-judgements could never be resolved, but nonetheless attempted to delineate the issues surrounding researcher bias.⁸² As is contemporarily promoted across various disciplines and research methodologies, Weber called for the disclosure of bias and stated that:

Only when the teacher sets as his unconditional duty, in every single case, even to the point where it involves the danger of making his lecture less lively or attractive, to make relentlessly clear to his audience, and especially to himself, which of his statements are statements of logically deduced or empirically observed facts and which are statements of practical evaluations. Once one has acknowledged the distinction between

⁸⁰ Picciuto.

⁸¹ Sven Eliaeson, *Max Weber's Methodologies* (Cambridge: Polity Press, 2002). P. 16.

⁸² Eliaeson. P. 26.

the two spheres, it seems to me that the assumption of this attitude is an imperative requirement of intellectual honesty; in this case it is a minimal requirement.⁸³

Dawkins is doing exactly what Weber warned against by claiming that his views on preventing the births of children with Down syndrome are rooted in logically deduced facts. The reality, however, is that Dawkins's views are conceived from practical evaluations, not facts at all. Weber was firm in his assertion that bias permeates most, if not all aspects of scientific research, even to the point that our personal biases are determining what phenomena is worthy of study, Weber states:

The concept of culture is a value-concept. Empirical reality becomes 'culture' to us because and insofar as we relate it to value ideas. It includes those segments and only those segments of reality that have become significant to us because of this value relevance. Only a small portion of existing concrete reality is coloured by our value-conditioned interest and it alone is significant to us. It is significant because it reveals relationships which are important due to their connection with our values. Only because and to the extent that this is the case, is it worthwhile for us to know it in its individual features. We cannot discover, however, what is meaningful to us by means of a 'presuppositionless' investigation of empirical data. Rather, perception of its meaningfulness to us is in the presupposition of it becoming an object of investigation. Meaningfulness does not naturally coincide with laws as such, and the more general the law the less the coincidence. For the specific meaning which a phenomenon has for us is naturally not to be found in those relationships which it shares with many other phenomena.⁸⁴

Thus, when Richard Dawkins tells us his views on people with Down Syndrome, he is relaying the information about his personal views on the matter, as well as how the existence of people who have Down syndrome fit into his world view. For many people, that view is not particularly attractive. As an evangelist for the concept of atheism and the promotion of the secularisation of public policy, Dawkins is associating his views on people with Down syndrome

⁸³ Max Weber, *The Methodology of the Social Sciences*, ed. Edward Shils and Henry Finch (Glencoe: The Free Press, 1949). P. 2.

⁸⁴ Weber. P. 76-77

with his social movement for atheism and secularisation. Is that what Dawkins intends? Is act-utilitarianism a method of atheism? Is atheism a scientific truth? The answers for these questions are no, but the message presented claims yes. Ultimately, facts are not independent of values and theories are not value-free.⁸⁵

Researcher bias as a methodological problem is perennially present and positivist, realist and conventionalist paradigms continue to have adherents. As methodologies have developed, however, the names of these paradigms have been refined and categorised further. Alongside positivism is ‘post-positivism’, which leans toward ontological and epistemological realism and is somewhat tolerant of qualitative methods.⁸⁶ Here the emphasis is placed on the replication of objective findings, with the understanding that all findings are falsifiable.⁸⁷ Still, the legitimacy of these traditional paradigms have been seriously threatened by ‘post-structural’ and ‘post-modern’ paradigms that challenge the notion that any one method or theory may make a claim of authoritative knowledge.⁸⁸ Post-structural and post-modern paradigms have proliferated over the last several decades and have generally pushed out those who still seek a value-free social science.

In a complete rejection of the researcher as a disinterested observer, the ‘critical theory’ paradigm holds that reality has been shaped by values and there is recognition that the researcher is aware that findings are value-mediated by both the researcher and the research participants.⁸⁹ The critical theorist aims to assist research participants to observe and understand the sources of

⁸⁵ Egon Guba and Yvonne Lincoln, “Competing Paradigms in Qualitative Research,” in *Handbook of Qualitative Research*, ed. Norman Denzin and Yvonne Lincoln (Thousand Oaks: Sage Publications, 1994). P. 107.

⁸⁶ Guba and Lincoln. P. 109.

⁸⁷ Guba and Lincoln. P. 110.

⁸⁸ Norman Denzin, “The Art and Politics of Interpretation,” in *Approach to Qualitative Research* (New York City: Oxford University Press, 2004). P. 448.

⁸⁹ Guba and Lincoln, “Competing Paradigms in Qualitative Research.” P. 110.

their oppression, and will take on an advocacy role to help research participants to solve problems.⁹⁰

The ‘constructivist’ paradigm exchanges realism for relativism and understands findings to be subjective.⁹¹ It is here that subjective findings are created during the course of research by a researcher that is linked with the research participants.⁹² At the innovative edge of social research are feminist methodologies that are critical, constructivist, interpretive and reflexive.⁹³ Thus, the spectrum of research paradigms moves from epistemological assumptions that knowledge is derived from purely objective findings to knowledge is derived from purely subjective findings that are collaboratively constructed by the researcher and the research participants.

Feminist constructivist methodologies embrace reflexivity and positionality as an attempt to reveal researcher bias and to produce more accurate and useful research. This method is performed when researchers make efforts to interrogate their own beliefs about the topic and the people that they study. All types of research, even quantitative, is subject to ‘experimenter effects’. Experimenter effects can occur when researchers are acting: “[u]nbeknownst to themselves to produce the effects they want and expect”.⁹⁴ At every stage of the data collection process, the researcher might succumb to biased interpretation and analysis. For example, when coding, the researcher can sub-consciously, or even consciously, select concepts in support of their personal worldview, while at the same time overlooking those concepts that are not in

⁹⁰ Peter Taylor and Milton Medina, “Educational Research Paradigms: From Positivism to Multiparadigmatic,” *Journal for Meaning Centred Education* 1 (2013), file:///C:/Users/britt/Downloads/IJMCETaylorMedina2013.pdf.

⁹¹ Guba and Lincoln, “Competing Paradigms in Qualitative Research.” P. 109.

⁹² Guba and Lincoln. P. 109.

⁹³ Norman Denzin and Yvonne Lincoln, *Handbook of Qualitative Research*, ed. Norman Denzin and Yvonne Lincoln (Thousand Oaks: Sage Publications, 1994). P. 102.

⁹⁴ Robert Weiss, *Learning From Strangers: The Art and Method of Qualitative Interview Studies* (New York City: The Free Press, 1994). P. 211.

support of their worldview. Yet, reflexivity and positionality are more than simple ‘navel gazing’.

Many researchers endorse systematic self-analysis of their beliefs in an attempt to discontinue reproducing the oppressive power structures that have traditionally existed within the dominant ‘ethnically white’ and patriarchal academic literature that is frequently judged to exclude women, non-whites, racialised ethnicities, and various groups that have been socially designated as ‘Other’. The goal is to capture the viewpoints and experiences of the research participants, not merely produce more ‘evidence’ that an oppressive policy remains functional. Academic attitudes toward policies of institutionalisation only evolved once interpretive studies framed institutionalisation as oppression, rather than medical practices rooted in empirical facts.

Reflexivity and positionality are not easy processes and, arguably, it requires a researcher that is confident and sophisticated enough to accept they might have harboured some epistemological errors about the nature of the world, and be willing to think about the world differently than they have in the past. Reflexivity can be defined as: “[r]ecognition on the part of the researcher that research is a process that contains a variety of power dimensions. It is crucial for researchers to become aware of their positionality—that set of attributes and identities they bring to the research setting, including their gender, their race/ethnicity, and their class position”.⁹⁵ Once the researcher is able to determine how their own experiences and interpretations are different than what others experience, the researcher can begin to isolate and categorise the meanings that other people attribute to things, rather than continue searching for and describing their own meanings for the same things. It is, after all, well recognised that different groups of people will ascribe different meanings to similar things. For example,

⁹⁵ Sharlene Nagy Hesse-Biber and Patricia Leavy, *Approaches to Qualitative Research* (Oxford: Oxford University Press, 2004). P. 133-134.

policies of institutionalisation meant something very different to a 1930s advocate of eugenics than it does in 2019 for a single mother of a child who has intellectual disability and no assistance to keep her child in his own home.

Increasingly, qualitative research that is believed to be ‘good’ includes researcher recognition of where they are located within the study and how this location has informed the study.⁹⁶ The consumer of the research product wants to know if the researcher was an insider or an outsider, if they are politically aligned with the research outcome, and if the researcher is aware of how their societal status is similar or very different than that of the research subjects.⁹⁷ In short, the researcher needs to demonstrate they are aware of their ontological and epistemological assumptions and the effect these assumptions have on the research. Additionally, there must be some recognition of the researcher’s orientation to the research participants. Is the researcher a member of the studied social group? Are they an outsider? Are they sympathetic to the points of view of the participants, or are they critical of the participants beliefs and actions? These are necessary issues to consider.⁹⁸

To understand why these issues are important, I offer the example of my Honours thesis regarding the rise and fall of the liberation theology movement in Latin America. While I found the concepts of liberation theology interesting, and very different than other theologies that I had been exposed to in my life, I had no interest in adopting Latin American liberation theology into my personal belief system. By saying that, I do not mean that I reject liberation theology or the people who embrace it. On the contrary, liberation theology is a much admired interpretation of Christian faith, the bulk of which has now been co-opted into the official teachings of the Roman

⁹⁶ Sandra Kirby, Lorraine Greaves, and Colleen Reid, *Experience Research Social Change: Methods Beyond the Mainstream*, Second (Toronto: University of Toronto Press, 2010). P. 36-37.

⁹⁷ Kirby, Greaves, and Reid.

⁹⁸ Kirby, Greaves, and Reid.

Catholic Church. Instead, I was interested in how this religiously inspired social movement arose, how it gained prominence, and how both civil and religious counter-revolutionary forces mobilised to suppress this social movement. As instructed by my supervisor, I had written up my research in what I believed to be the voice of the disinterested observer, but the response from the committee was an assumption that I was a Liberationist myself and was advocating for liberation theology (not that they were opposed to me taking that position). How an English speaking, white, military wife living in rural Nova Scotia, who was raised Pentecostal, could be perceived as being a member of a Roman Catholic social movement in Latin America that fizzled out a good twenty years before she first heard about it-- STILL mystifies me. Yet, that is what happened.

Clearly, there is a fine line between displaying empathy toward one's research participants and taking on their revolutionary cause. In retrospect, I now realise that much of the confusion has to do with an individual's adherence to paradigmatic boundaries. Latin American liberation theology was influenced by Marxism, and truly, most of the reason this social movement was of interest to me was the idea that Marxism and religion could syncretise to become such a powerful social group. I came to understand that some people had difficulty with this concept based on their standpoints. For example, some Marxists expressed an opinion that liberation theology was "doing Marxism wrong" and was therefore irrelevant to what mattered to them. As well, some Christians, of various denominations, believed that the embrace of Marxist principles by Liberationists made them heretics and that the entire liberation theology movement was "doing Christianity wrong". For me, it was not important that people were doing Marxism or Christianity right or wrong, nor do I believe that such things are possible. Yet, however, I continue to believe that it was wrong for Protestant Christian groups to assist Latin American

governments with funding and arming para-military forces to suppress and even kill liberationists –just one example of my own standpoint relevant to these issues. The point here is that one does not have to be an insider to have empathy for an oppressed group, but it is quite common for outsiders to overlook an oppressed group due to lack of interest or lack of conformity with their own world view.

The same thing happened again when I began to research the Roman Catholic women's ordination movement, which was a social movement that I became interested in because the issue of ordaining women was argued to have been a major catalyst for diffusing the social movement for liberation theology. Apparently, the ordination of women was a liberation too far for many Liberationist priests. Rejecting the notion that women were meant to be excluded from the apostolic line of succession, an international social movement arose where some women managed to attain ordination via male priests that were willing to break a few rules. It was all very fascinating, and topical considering that members of this social movement were engaging in high profile ordinations of one another that were catching the attention of the international media. Still, many colleagues failed to understand why the Roman Catholic women's ordination was relevant. Some people expressed that Christianity was dying out, so there was no point to studying anything to do with it. Other people expressed that these women were heretics and of no consequence. There was even some complaint that my topic was better suited to be framed through a feminist methodology rather than the methodology that I used.

The lesson here is that it is useful for the researcher to deliberately delineate where one stands within the research field so that there will be no confusion about what the research is attempting to say. What I had hoped to convey was how diverse theologies can be, even within the same religion, and how these theologies are constructed through engagement with the

political structures of the State. Importantly, I was writing about how theologies can become tools of either oppression or liberation, serving the interests of both revolutionary and counter-revolutionary movements. Instead, it appears that I gave the impression that I had found the one true answer to social inequality. Some of this can be attributed to the immaturity of my scholarly development, but these examples show how dependent the research product is upon the researcher's assumptions about the world.

As well, I have noticed that consumers of research tend to make assumptions about the researcher based on the subject matter, and that I am not the only researcher to have been assumed to be a participant within the groups studied. I had a colleague that studied a group that engaged in a very unusual sexual practice, and she became horrified to learn that it became widely assumed that she also engaged in this practice. In another instance, a colleague studied illicit drug use within a certain population, and it again became widely assumed that he knew so much about his topic because he was a user of these drugs himself. Therefore, it is reasonable to be concerned that the 'disinterested' voice does not sound as disinterested as we hope. If nothing else, locating oneself within the research clarifies who the researcher is, and assists the reader to distinguish between the identity of the researcher and the research participants. In failing to locate myself within my earlier work, I was unable to appropriately crystallise my message, and going forward, I must attend to this problem.

The characteristics of research differ based on the paradigm adhered to. Positivist and post-positivist inquiry hope to explain, while the interpretive critical and constructivist paradigms hope to understand.⁹⁹ At the same time, positivist and post-positivist studies attempt to exclude and deny the influence of value-judgements, while the interpretive critical and

⁹⁹ Guba and Lincoln, "Competing Paradigms in Qualitative Research." P. 112.

constructivist paradigms assert that value-judgements permeate and inform inquiry.¹⁰⁰ Of special interest is the ‘voice’ of the researcher, with positivist and post-positivist paradigms presenting themselves as disinterested scientists disseminating knowledge, while the interpretive critical and constructivist researchers position themselves, to varying degrees, as advocates and participants within their fields of study.¹⁰¹ In general, the positivist and post-positivist researchers find themselves sceptical of the constructivist arguments relating to reflexivity and positionality, and yet, my above example describes a situation where care was taken to appear objective, not let value-judgements infect the text, but the readers were given the entirely wrong impression. Care must be taken, therefore, to ensure that the desired point reaches the reader of the research.

The social movements for de-institutionalisation and inclusion are not very different than the earlier social movements that I have studied. Each social movement has been rooted in a desire to overcome oppression and achieve social justice. In each situation, the social movement has had to strive against deeply entrenched social values supported through the institutions of the State and/or the Church. Crucially, I desire that my readers understand that I am an empathetic outsider to the social movements for de-institutionalisation and inclusion. I believe that people who have intellectual disability have the right to exist and to be full members of the community. I will even go as far to state that people who still insist that people who have intellectual disability have no worth and that should be excluded from the community are “doing humanity wrong”. Although my voice may sometimes appear to reflect that of the disinterested observer, there should be no ambiguity concerning whether I am neutral on the topics within this dissertation. I have judged policies of institutionalisation to be harmful in both their historical and contemporary forms. Likewise, I hold no sympathy for the advocates of eugenics and I

¹⁰⁰ Guba and Lincoln. P. 112.

¹⁰¹ Guba and Lincoln. P. 112.

believe that such advocates were and continue to be responsible for disseminating harmful ideologies in the guise of science. Furthermore, I believe that eugenics and policies of institutionalisation in Canada are products of British colonialism, and that the de-colonisation of Canada, and its various peoples, necessarily involves a serious and reflexive self-interrogation of our colonial heritage and our individual roles within that heritage.

Competent scholars should be engaged with how their values might be used to oppress others—especially as there is the benefit of thousands of years of recorded epistemological debates regarding what is fact and what is opinion. Recently, there has been an increase in the number of studies that explore social injustice as an agent of colonisation, and there is a great deal of reported evidence that suggests that colonised peoples continue to experience lower health outcomes.¹⁰² Additionally, over the last 100 years, there has been a great deal of scholarly work that frames policies of institutionalisation as methods of control over impoverished populations, especially when they are apt to become involved in resistance against the dominant class.¹⁰³ Of special note, there is a substantial literature that reveals how the meaning of intellectual disability has been historically associated with inability or reluctance to participate in the local economy.¹⁰⁴ Ultimately, there exists a large enough body of literature that the academically focused policy analyst should be aware of the arguments relating the concepts of colonialism, institutionalisation, eugenics, social inequality and social control; and all policy analysts need to know where they stand within these debates.

¹⁰² Kalinda Griffiths et al., “How Colonisation Determines Social Justice and Indigenous Health -- a Review of the Literature,” *Journal of Population Research* 33, no. 1 (2016).

¹⁰³ Ranjana Khanna, “The Lumpenproletariat, the Subaltern, the Mental Asylum,” *South Atlantic Quarterly* 112, no. 1 (2013).

¹⁰⁴ Mark Rapley, *The Social Construction of Intellectual Disability* (Cambridge: University of Cambridge Press, 2004).

As methodologies mature, diverse researchers have a tendency to mix and match methods as: “[v]arious paradigms are beginning to ‘interbreed’ such that two theorists previously thought to be in irreconcilable conflict may now appear, under a different theoretical rubric, to be informing one another’s arguments”.¹⁰⁵ The ‘multi-paradigmatic’ approach is useful for the researcher as it allows for innovation and enhances the professional development of the researcher.¹⁰⁶ Such a description is relevant to this dissertation in that concepts were borrowed from methodologies across the paradigmatic spectrum, and the constructivist form of grounded theory methodology is in itself a multi-paradigmatic approach. Since paradigms are merely ideal types, the margins between them tend to be fuzzy in the first place.

Max Weber described an ideal type as: “[s]tatements of general form asserting the existence of certain constellations of elements which are empirically only approximated by the instances of the class phenomena to which each type refers”.¹⁰⁷ In other words, an ideal type is a conceptual tool that allows the categorisation of phenomena into sets of ideas that are relevant to the culture they arise within. Thus, the concept of institutionalisation is an ideal type, while the concept of de-institutionalisation is another. When sorting ideas, we would associate the concept of inclusion with de-institutionalisation rather than institutionalisation, as institutionalisation has historically had the goal of segregation, while inclusion is a goal of de-institutionalisation. Yet, institutionalisation and de-institutionalisation are not concrete objects. They involve ideas about the world that were inter-subjectively constructed by people and are therefore abstract concepts. Not only might the parameters of what institutionalisation means change from culture to culture,

¹⁰⁵ Yvonne Lincoln and Egon Guba, “Paradigmatic Controversies, Contradictions, and Emerging Confluences,” in *Handbook of Qualitative Research*, ed. Norman Denzin and Yvonne Lincoln, 2nd ed. (Thousand Oaks: Sage Publications, 2000).

¹⁰⁶ Taylor and Medina, “Educational Research Paradigms: From Positivism to Multiparadigmatic.”

¹⁰⁷ Thomas Burger, *Max Weber’s Theory of Concept Formation* (Durham: Duke University Press, 1987). P. 133.

but what is recognisable as an institution in one culture might be unrecognisable and non-existent in another culture.

People's actions are oriented toward the meanings that they ascribe to the world they inhabit, and these meanings about the world are inter-subjectively constructed.¹⁰⁸ In regard to institutionalisation and de-institutionalisation, each domain was constructed by the meaning that was ascribed to people who have disability and their place within the world. Thus, non-empirical assumptions arose in the development of policies of institutionalisation that became treated as empirical truths. For example, the ideas that intellectual disability is the cause of poverty and that people who have intellectual disability should be segregated from mainstream society became scientifically derived truths, and yet they are not truths at all, scientific or otherwise. At the same time, the process of de-institutionalisation is rooted in contemporarily assumed truths concerning the ideal form of economic organisation and the delivery of welfare to vulnerable people.

In acceptance of the constructivist paradigm, I personally agree that social reality is inter-subjectively constructed by people and that all social action is oriented toward the constructed meanings that people attribute to things, themselves, and others. I have long been persuaded that 'scientific facts' are encumbered with value-judgements, and although I will regularly make use of quantitative data produced by other researchers, I do so with the understanding that this sort of data has a tendency to be based on loaded survey questions, a scrubbing of outliers, and the bounded rationality of respondents. In general, I view such data as another category of meanings—an ideal type consisting of a set of ideas about the world that might be a little fuzzy at the edges. More important than producing empirically derived facts, quantitative surveys can

¹⁰⁸ Herbert Blumer, *Symbolic Interactionism: Perspective and Method* (Berkeley: University of California Press, 1969). P. 2.

shed light on the constructed realities of human societies, thus offering us a glimpse of the effect of Durkheimian ‘social facts’. Durkheim defined social facts as: “[m]anners of acting, thinking and feeling external to the individual, which are invested with a coercive power by virtue of which they can exercise control over him”.¹⁰⁹

Although social facts are real in the sense that they provide social consequences to those that are subject to them, they are not truly real. They are constructed by people. Thus, policies of institutionalisation produced social facts that had real consequences for people who have disability. The Saskatchewan Training School and the later Valley View Centre offered real consequences for people who have intellectual disability, but they were not built from scientific facts. They were built out of value-judgements, now discarded economic tools, and scientific errors. They were the brick and mortar manifestations of a form of social coercion and control that is now obsolete—at least in terms of the social control of people who have intellectual disability. Policies of institutionalisation remain in effect for various other populations.

It is necessary to attend to the issue that the grounded theory method is not nearly as constructivist in its form as I profess to be. When Glaser and Strauss first developed their methodology, they intended it as bridge between quantitative and qualitative sociological methods.¹¹⁰ Their dreams of an empirical qualitative method ultimately failed, however, as even the empiricism of quantitative research is in question. Glaser and Strauss eventually went their separate ways, and a constructivist framework for grounded theory methods emerged. It remains possible, however, for some researchers to embrace what they perceive as the more positivist aspects of the grounded theory method, while other researchers may embrace the more

¹⁰⁹ Emile Durkheim, *The Rules of the Sociological Method*, ed. Steven Lukes (New York City: The Free Press, 1895).

¹¹⁰ Strauss and Glaser, *The Discovery of Grounded Theory: Strategies for Qualitative Research*.

constructivist aspects. What grounded theory methods offer the constructivist researcher are tools for the collection, organisation and analysis of data.¹¹¹ At the same time, the constructivist researcher is under no illusions that the collected data and theories generated are not influenced by their own value-judgements.

The constructivist approach to grounded theory recognises the interactive relationship between the researcher and the research participants as well as the position of the researcher as author.¹¹² Importantly, the constructivist approach demands that the researcher is reflexive concerning their own assumptions about the research topic and discloses these assumptions to the reader.¹¹³ Thus, the foundations of a constructivist grounded theory project should generate theory that is grounded in both the researcher and research participant's experiences, clarify the power imbalances between the researcher and the participants and work to alleviate them, and make clear the position the author takes within the text.¹¹⁴

The relationship between the researcher and the participants is important and trust must be carefully cultivated. This is because the researcher and the participants are engaging in the co-production of meaning and producing research that is mutually negotiated. For example, the members of the VVCTSC needed confirmation that I was not there to criticise their struggles or their values. Efforts were made by the participants to ensure that I was aware of the values of inclusion and the need for their advocacy work, with the hope that I was receptive of these ideas. These fears were rational as advocates for inclusion and de-institutionalisation often experience opposition to their values and spend considerable resources on raising awareness.

¹¹¹ Charmaz, "Grounded Theory."

¹¹² Jane Mills, Ann Bonner, and Karen Francis, "Adopting a Constructivist Approach to Grounded Theory: Implications for Research Design," *International Journal of Nursing Practice* 12 (2006). P. 2.

¹¹³ Mills, Bonner, and Francis. P. 2.

¹¹⁴ Mills, Bonner, and Francis.

In any project, the researcher holds significant power, which must be recognised and mitigated. Research participants are never quite sure what the researcher will write about them, and in the case of the Valley View Centre, the research participants also seemed nervous about what the results of my research would be. Would I represent their values and work accurately? Would I judge the transition of Valley View residents to the community to be a success, or would I take the stand that the Valley View Centre should remain open? Would I somehow embarrass the VVCTSC? To alleviate these worries, I informed the VVCTSC in writing that they would be given the opportunity to inspect my penultimate draft to ensure that I had represented values and events accurately. It was not until they were provided with the finished text, however, before fears were finally alleviated. In the future, I will plan to provide research participants with samples of written text at an earlier stage in the hope of fostering trust and relieving anxiety.

Despite coming to this research project knowing very little about institutionalisation, de-institutionalisation, inclusion, disability policies and people who have intellectual disability, I nevertheless possessed various assumptions about these topics. In the process of conducting the research, my attitudes and assumptions evolved. I had known nothing about the care needs of people who have intellectual disability, and I certainly had no idea that other attempts to close institutional facilities had failed. The state of my ignorance was so deep that I was an ideal candidate to embark on research using grounded theory methods—maintaining the assumption that bias may be reduced when the researcher supposedly does not have any pre-conceived ideas about the subject matter. Yet, in the process of learning about these issues, I came to understand that I had suffered from misguided assumptions. I certainly held pre-conceived ideas about my research topic, I was just not aware of them. I soon realised that the principles of

institutionalisation had become so entrenched within Canadian culture that a person like me, who is educated and knowledgeable about many things, harboured misguided assumptions. As my exploration of de-institutionalisation progressed, I realised that I was far from the only person lacking a grasp on the issues, and I determined that my work must include a definitive description of what institutionalisation truly is, and why de-institutionalisation should be pursued.

It is advised that the grounded theorist keep a journal to track their thoughts and interrogate their own bias concerning the subject matter.¹¹⁵ Throughout the course of my study, my journal notes have revealed my own transition to becoming an advocate for de-institutionalisation and inclusion. In my initial entries, I wondered how the closure of the Valley View Centre could be completed more economically and maintain the social safety net that a facility such as this could provide. By the end of the study, I had recognised that people who have intellectual disability have the right to participate in the community, and to receive care in the community, rather than a segregated institutional facility. It is not that I formally thought that people who have intellectual disability should be segregated from society, rather, it is that I did not know what segregation from society meant. I was unaware of the original functions that institutional facilities had, and what sort of effect these facilities have had on the people who lived within them. Now I know better, but I should have known better in the past.

As far as I am aware, only one member of my family has ever been diagnosed with an intellectual disability, and therefore I did not have very much experience. He was the nephew of a stepparent, and as an adult, I now realise that everything that I had ever been told about him was inaccurate. I was told that he had schizophrenia, but in retrospect, I know that was likely not

¹¹⁵ Mills, Bonner, and Francis.

his diagnosis, but rather a ‘catch-all’ label that was easier for his family to understand. For one, my cousin was not old enough to be diagnosed with schizophrenia, but if he did have schizophrenia, it was part of a dual diagnosis. Although I was a few years younger than him, I noticed that he did not walk like other children and that he required constant supervision. We got along fine and he gave me a transistor radio that I reluctantly had to give back after being told that my cousin constantly gave things away, but he didn’t really mean it.

When my cousin reached his late teens, he was admitted to Riverview Hospital. His mother had waited for years for him to receive a bed at this institutional facility, and my family believed this was the best thing for my cousin. Although his mother clearly loved him, I remember that other members of the family were far less enthusiastic about him, thinking that he was dangerous. My Aunt was conflicted about keeping her son in Riverview Hospital, and I know that my cousin wanted to return home. There were few options for him, however, as my Aunt was a single mother and she had very few financial resources. It was either a bed at Riverview Hospital or live at home without any support at all.

During this era, I was aware that the Riverview Hospital was not considered to be a very nice place and that it was a place where ‘bad’ people went. During the entire period that I knew him, I was told that my cousin was ‘bad’. Not only did my Aunt have no State support to care for her son at home, but she had no family support either. It was not just my family, however, as the community was quite alarmed when Riverview Hospital started allowing residents to have day passes. Since the facility was located at the junction of several traffic arteries, thousands of daily commuters began to observe residents leaving and entering the hospital grounds and this caused quite a stir. A widely discussed community concern regarded what could happen if these ‘dangerous patients’ did not return to the facility.

As it turns out, Riverview residents did occasionally run off, and my cousin was one of them. When my cousin ‘escaped’ there was a great deal of media attention, especially regarding how the care facility had not kept an appropriate eye on him. The police searched for him for days, and his body was eventually found only a few kilometres from our home. The autopsy revealed that he had succumbed to hypothermia as he hid in the woods, likely hoping to avoid capture by the police. After his death, I only heard my cousin spoken about in very rare circumstances, and usually in connection with a perceived need for ‘better security in these sorts of hospitals’.

I had always assumed that my cousin had run away due to his illness—perhaps he had heard voices telling him to leave the facility and hide in the woods. I now understand that there was much more to consider. Since there had always been some worry about the suitability of Riverview Hospital to care for my cousin, it was apparent that he did not like living there. Based on reports of what routinely occurred in other institutional facilities, my cousin was likely subjected to harsh punishments for some of his behaviours, including electro-shock therapy, isolation, and being placed in restraints. These punishments would have been accompanied by the high stress situation of custodial care alongside hundreds of people that were experiencing psychosis and other difficulties. It is probable that my cousin ran away from the Riverview Hospital for the same reasons that many others have run away from institutional facilities—because it was a terrible place that they wanted to be free from.

Now, when I consider what happened to my cousin, I contemplate a tortured and frightened young man who took a chance at freedom. I expect that he hid himself so well in the woods that the police couldn’t find him because he feared what would happen if he was caught and returned to the institutional facility. Not even extreme cold and hunger could coax him from

his hiding place, and he was just one of countless individuals with a similar story. Importantly, the exact location where my cousin's body was found was telling. He may have been close to our house, but he was on the highway that led to his mother's house. My cousin wasn't escaping. He just wanted to go home.

Living at home, however, is not always enough, even if the best care possible is provided within the home. People who have disability continue to be 'Othered', especially those people who have intellectual disability. Instead of first being viewed as people, people who have disability are frequently defined by their disability, rather than by their actions or personalities.¹¹⁶ Thus, it does not matter how much a child is loved and cared for at home, if the larger society is unwilling to accept them. Helping to transition societal attitudes from segregation to inclusion takes time and effort.

The first time that I was introduced to issues of inclusion was when I was 16. My high school had a special education program and it was arranged that my Language Composition class would visit the special education students to "meet them and learn about them". We were told that the special education students had intellectual disability and what to expect from our visit with them. Everyone seemed satisfied to participate except for one fellow student who was a close friend of mine. This friend was very sensitive about the topic of intellectual disability as she had a brother that had been institutionalised since birth, and she had a very different viewpoint than the inclusion advocates that had arranged the activity. Not only did she refuse to participate, but she loudly expressed her anger that such an activity would be entertained at all. For reasons that I still do not understand, she believed that it was cruel for us to interact with the

¹¹⁶ Virginia Oleson, "Feminisms and Models of Qualitative Research." P. 160.

special education students, and that we were mocking her, her family, and the special education students.

Now that my understanding of these issues has been enhanced, I can now see that this event was a confrontation between the values of inclusion and the values of institutionalisation. Clearly the special education program was attempting to introduce integrated activities with students who had intellectual disability and typical students, but social attitudes were still in a state where even assumed allies resisted these attempts. The event itself was a one-off. The participating students went down to the special education classroom and sat at tables with the special education students. After enjoying a cookie and a drink, we collectively worked on some jigsaw puzzles that were appropriate for children between the ages of 3 and 5. I remember that my partner was unable to put the jigsaw puzzle together by himself, and that I would point out which piece he could use next. We completed that puzzle over and over until it was time to return to my own classroom. Interestingly, I do not believe that I would have remembered this event at all if it were not for the extreme negative reaction of my friend.

Today, the social movements for de-institutionalisation and inclusion continues to experience opposition. This not because the contemporary attitudes are to oppress people who have intellectual disability, but rather, because people are conflicted over how the ‘truths’ of the past have been replaced with new ‘truths’. Many well-positioned and respected ‘scientists’ once told us that people who have intellectual disability belong in segregation. Now we are being told those ‘truths’ were false and that people who have intellectual disability should be included in the community. In the context of Thomas Kuhn’s writings on shifts in the acceptance of scientific paradigms, these changes in societal attitudes are part of the transition from old ideas to new ideas. The scientific community enjoys consensus that institutionalisation is no longer the

best practice to care for people who have intellectual disability, but it has taken the general population longer to understand these issues. Convincing people that a once deeply institutionalised truth statement is now false is difficult. It may be even more difficult to de-institutionalise societal attitudes than it is to de-institutionalise an institutional facility, which has turned out to be quite difficult. Yet, advocates of inclusion and de-institutionalisation continue to achieve success one small brick at a time. My hope is that my message is clear that I believe their mission to be worthy.

Chapter 3

The De-institutionalisation of People who have Intellectual Disabilities through De-construction of the Welfare State

The process of de-institutionalisation has had two narratives. The first of these narratives is the story of de-institutionalisation as the result of a social movement that advocates for the full community participation of people who have intellectual disability. These de-institutionalisation advocates have long asserted that the institutional model of care has failed, and that care within the community is best. The second story of de-institutionalisation is how the process of de-institutionalisation has been related to the de-construction of the welfare state. Within this context, the de-construction of various welfare state policies has involved replacing state-run institutional facilities with health care markets.

More generally, the term ‘welfare state’ refers to the developed set of services and benefits a government has made available to citizens, with the goal of protecting them from hardship and destitution. Examples of welfare benefits and services might include income support, health care insurance, subsidised housing, and old age pensions. Different nations, and even different provinces and states within nations, develop individual welfare state programs

based upon favoured regional political ideologies and specific requirements. That means that the responsibilities taken on by federal governments often differ from the responsibilities taken on by provincial or state governments. As well, different nations interpret social responsibilities of the state differently, and therefore, their individual welfare states may take vastly different forms, with all systems evolving over time in line with changing ideologies, shifting circumstances, and different fiscal realities.

Although widespread use of the term ‘welfare state’ only arose in the wake of World War II, welfare states have existed throughout history. In ancient Greece, for example, legislation was developed to provide social assistance to Athenian soldiers in 600 BCE.¹¹⁷ It has been suggested that welfare states arise out of the economic growth of a nation.¹¹⁸ As economies develop and grow, the negative impacts of social inequality also increase. The extent of a welfare state is dependent upon how much social inequality a society is willing to tolerate, as well as societal attitudes toward the causes of poverty and the best means of alleviating inequality.

After World War II, many industrialised nations deeply invested in their individual welfare states. This investment demonstrably alleviated social inequality. For example, social inequality in the United States fell substantially between 1950 and 1980, before expanding greatly between 1980 and 2020.¹¹⁹ In 1980, the top 10% of earners took 30 to 35% of the national income, but by the 2000s, these top earners were taking between 45-50% of the national income.¹²⁰ That means that Americans have now returned to a similar level of social inequality

¹¹⁷ Bent Greve, *Historical Dictionary of the Welfare State* (Lanham: Scarecrow Press, 2006). P. xiii.

¹¹⁸ Harold Wilensky, *The Welfare State and Equality: Structural and Ideological Roots of Public Expenditures* (Berkeley: University of California Press, 1975). P. xiii.

¹¹⁹ Thomas Piketty, *Capital in the Twenty-First Century* (Boston: Harvard University Press, 2014). P. 294.

¹²⁰ Piketty. P. 294.

experienced in the 1920s when the top earners took 50% of the national income.¹²¹ By 2030, the top U.S. earners are projected to take in 60% of the national income.¹²²

Political ideologies that advocate for market liberalism have gained favour in Great Britain, Canada, Australia, and the United States, which led to debates concerning the role of the state in welfare provision.¹²³ The wide acceptance of liberal ideologies have led several nations to disassemble their post-war welfare state economies. One of the outcomes from this widespread reconsideration of the nature of the welfare state has been the closure of numerous institutional facilities. Like many other western liberal democracies, Canada has generally accepted the main principles promoted by the social movement for de-institutionalisation, and individual provinces have made policy decisions in support of de-institutionalising their vulnerable populations. To achieve their goal, governments have privatised many social services. Within Saskatchewan, policies in support of community care have been implemented incrementally since the 1950s, but it was not until after 2011 when the Government of Saskatchewan chose to seriously pursue a project of de-institutionalisation for people who have intellectual disabilities. In Saskatchewan, the slow progress toward de-institutionalisation can be attributed to both policy drift and a perceived lack of opportunity.

The process of de-constructing welfare states has both assisted and thwarted the goals of social movements for de-institutionalisation. As well, the effects of privatisation policies have created mixed results within the architectures of local systems of care. Although many studies have concluded that community care has resulted in better outcomes for people who have disabilities, systems of care tend to remain fragile. Advocates for de-institutionalisation remain

¹²¹ Piketty. P. 293.

¹²² Piketty. P. 294.

¹²³ Julia O'Connor, Ann Shola Orloff, and Sheila Shaver, *States, Markets, Families* (Cambridge: Cambridge University Press, 1999). P. 1.

concerned that gaps in services continue to exist, and that health care markets continue to suffer from underfunding.

Institutionalisation versus De-institutionalisation:

De-institutionalisation is the deliberate de-construction of institutionalisation. Policies of institutionalisation were originally created to allow governments to provide care for vulnerable persons. People were believed to be ‘vulnerable’ when they were deemed physically or mentally incapable of independent participation in the economy.¹²⁴ For example, the 1913 Mental Deficiencies Act ensured that British people who had intellectual disabilities were segregated from the main population.¹²⁵ Similar policies and legislation were employed throughout the British Empire and its former colonies, which included Canada and several other nations. At the time, segregation was thought to be a safeguard against the perceived harms that would result if the ‘feeble-minded’ were permitted to inter-breed with the general population.

During the early 20th century, many nations were creating social policies rooted in eugenics, and governments were accepting of ideologies asserting that humans could improve their genetic make-up through selective reproduction. Some members of the middle and upper classes were alarmed about the high birth-rate of the poor, as it was believed that poor people were less intelligent than other members of society.¹²⁶ Organisations such as the Eugenics Education Society lobbied for legislation that not only would protect society from those believed to be ‘defective’, but also for the protection of these vulnerable people themselves.¹²⁷

¹²⁴ Robin Means, Sally Richards, and Randall Smith, *Community Care*, ed. Colin Fudge and Robin Hambleton, *Public Policy and Politics*, 4th ed. (Houndmills: Palgrave Macmillan, 2008). P. 40.

¹²⁵ Jan Walmsley, “Institutionalization: A Historical Perspective,” in *Deinstitutionalization and People with Intellectual Disabilities: In and Out of Institutions*, ed. Kelley Johnson and Ranveig Traustdottir (London: Jessica Kingsley Publishers, 2005). P. 52.

¹²⁶ Means, Richards, and Smith, *Community Care*. P. 34.

¹²⁷ Walmsley, “Institutionalization: A Historical Perspective.” P. 55.

For the proponents of eugenics, there was a great deal considered to be at stake. Not only was there a belief that ‘mental defectives’ are prone to low morality, but there was a fear that allowing them to reproduce would endanger Britain’s ability to maintain its empire.¹²⁸ Therefore, it had become the popular assumption that vulnerable people had to be somehow ‘cared for’, for their own protection, and for the protection of society. On the frontiers of the British Empire, such as the territories and provinces of western Canada, legislation such as the Mental Deficiency Act were believed to be an effective tool for ‘civilising’ the population.

Besides segregation, Britain’s Mental Deficiency Act officially categorised types of individuals regarded as defective. These types were labelled as ‘idiots’, ‘imbeciles’, feeble-minded persons’, and ‘moral defectives.’¹²⁹ The addition of the vague term of ‘moral defectives’ to the Act provided authorities with substantial power to institutionalise any people that did not conform to societal norms. Individuals were often remanded to institutional facilities because they were considered emotionally unstable, socially incompetent, promiscuous, disobedient toward parents, were children that had been neglected or abandoned, were habitually drunk, or they had given birth to an illegitimate child.¹³⁰ The policy of institutionalisation was not merely a program to organise the needs of people who have disabilities, it was also a method of social control that did not appear to distinguish between those who had disabilities and those that were considered to be criminal or delinquent, or even people that were simply unwanted. As a method of social control, the institutional facility was believed to be a place where ‘deviant’ individuals could be ‘reformed’. Furthermore, attitudes toward people who had intellectual disability were

¹²⁸ Means, Richards, and Smith, *Community Care*. P. 34.

¹²⁹ Walmsley, “Institutionalization: A Historical Perspective.” P. 56.

¹³⁰ Walmsley. P. 56.

so negative that it was believed necessary to segregate them even within populations of institutionalised people, such as away from those who had mental illness.¹³¹

It was possible to gain release from an institutional facility if an individual were able to demonstrate that they were now of a ‘good moral character’ and were believed to be able to succeed in the community: “[w]ithout being exploited...or causing difficulty to his environment”.¹³² These conditions of release reveal the double function of institutionalisation as a tool to both protect vulnerable individuals from society, and to protect society from morally deviant individuals. Overall, institutional facilities were perceived by the public as a place where ‘bad’ people went.¹³³ Furthermore, people who had intellectual disabilities were categorised within a larger group of individuals that society had deemed morally unacceptable, and this attitude contributed to a situation of poor living conditions and lack of agency for the institutionalised.

The bricks and mortar of institutional facilities are not the force that segregates the institutionalised, and this is true even when considering the reality that residents were unable to leave these facilities without permission. Douglas North defines institutions as the: ‘[r]ules of the game in society’.¹³⁴ What North is referring to here is that institutions are constraints that are designed to structure social action.¹³⁵ Moreover, these institutional constraints have the ability to define behaviour and limit the choices available to the actor.¹³⁶ When an individual is unable, or unwilling, to conform to the accepted ‘rules’ of behaviour, policies of institutionalisation have

¹³¹ Means, Richards, and Smith, *Community Care*. P. 33.

¹³² Walmsley, “Institutionalization: A Historical Perspective.” P. 34.

¹³³ Kelley Johnson and Rannveig Traustadottir, “Deinstitutionalization and People with Intellectual Disabilities: In and Out of Institutions” (London: Jessica Kingsley Publishers, 2005). P. 74.

¹³⁴ North, *Institutions, Institutional Change and Economic Performance*. P.3.

¹³⁵ Douglass North, *Institutions, Institutional Change, and Economic Performance* (Cambridge: Cambridge University Press, 1990). P. 3-4.

¹³⁶ North. P. 4.

served to ensure that ‘deviant’ actors are segregated from mainstream society until they conform. Thus, North asserts that the major role of an institution is to reduce uncertainty through the establishment of a stable set of norms.¹³⁷

The use of institutionalisation as a form of social control may be framed through Max Weber’s explanation of bureaucracy. Weber asserts that Western society, which is culturally prone to venerating rationality, is organised through the bureaucratisation of social norms. For example, in his work on “The Rational and Social Foundations of Music”, Weber argues that Western music is not only unique in its structure, differing from both ancient and other cultural forms of music, but that it evolved into increasingly rational forms that culminated in the orchestra, which is highly organised and only functions by tightly adhering to a set of bureaucratised rules.¹³⁸ Thus, the orchestra is an institution comprised of various rules and norms that are followed by the musicians within them. Those unwilling to conform to the rules of orchestral music will rarely be invited to play that form of music again. In the same manner, individuals deemed to deviate from the norms of accepted behaviour were required, through policies of institutionalisation, to be segregated from the larger community until they were able to perform to the accepted standards. The facilities used to house and segregate people who have disabilities depend upon a highly bureaucratised structure of norms in order to either ‘control’ or ‘reform’ people. The purpose of bureaucracy is to operate with the efficiency of a machine, ensuring functioning that is fast, unambiguous, and cost-effective.¹³⁹

¹³⁷ North. P. 6.

¹³⁸ Randall Collins, *Max Weber: A Skeleton Key* (Newbury Park: Sage Publications, 1986). P. 64-66.

¹³⁹ H H Gerth and C Wright Mills, “From Max Weber: Essays in Sociology” (New York: Oxford University Press, 1946). P. 214.

Ultimately, in large institutional facilities, bureaucratisation is a necessary tool to control populations of thousands of institutionalised people.¹⁴⁰ Within the institutional facility, the residents are subjected to regimented organisation of the smallest details of living. This includes when to get up; what to wear; when to eat; what to eat; how to behave; and what activities are permitted. Non-conformity is punished. Max Weber asserted that such regimentation of behaviour is rooted in the Western cultural embrace of ‘rational capitalism’, which favours ‘calculable rules’ to create ever increasing efficiency.¹⁴¹ Thus, both institutionalisation and de-institutionalisation can be understood through the Weberian lens as concepts that are embedded in the economic basis of rational capitalism. Since there have been major shifts in how many western liberal democracies have organised their capitalist economies, the methods of delivering social services have followed the economic changes.

While policies of institutionalisation were once constructed in support of historical forms of economic organisation, policies of de-institutionalisation are constructed in support of the contemporary form of economic organisation. That is not to say that proponents of either institutionalisation or de-institutionalisation are solely focused on the economic organisation of society. On the contrary, most proponents of either institutionalisation or de-institutionalisation see themselves as social reformers, rather than economists. When social reformers have argued the benefits of either institutionalisation or de-institutionalisation, they have done so within the bounded realities of the economic organisation of their day, which are so entrenched within the fabric of society that they tend to be invisible to many people.

¹⁴⁰ David Braddock et al., “Public Spending for Developmental Disabilities in the United States: An Historical-Comparative Perspective,” in *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, ed. Roger Stancliffe and Charlie Lakin (Baltimore: Paul H Brooks Publishing, 2005). P. 29.

¹⁴¹ Gerth and Mills, “From Max Weber: Essays in Sociology.” P. 215.

The Realities of Institutionalised Life:

Advocates for de-institutionalisation consider residence in an institutional facility to be an unnecessarily difficult living situation. There are many examples of institutionalised people whose stories have inspired proponents of de-institutionalisation. One of these examples, Tom Allen, spent 60 years of his life in various institutional facilities after he contracted polio as a child.¹⁴² Throughout his life, Allen had been diagnosed with varying degrees of intellectual disability. In 1928, he was first labelled as having an IQ of 37. Then in 1973, Allen's diagnosis was changed to 'borderline mental retardation'. Finally, in 1979, it was determined that Allen was 'non-mentally retarded'.

Tom Allen describes his treatment in institutional facilities as violent and abusive, and that: "[n]o one understood me or cared about me", and that: "[I] was punished for not behaving – often severely. The staff would, for example, put me on the floor in the back of the bathroom door and I had to lay there all day; sometimes without getting anything to eat".¹⁴³ Allen also recalls having to get up each morning at 5:30 a.m., and then being sat in a lounge for the entire day with nothing to do.¹⁴⁴ Allen remembers that: "[t]here were no programs in those days. No school. No work. No physical therapy. No speech therapy. No Nothing. I had hoped to get some education in Rome¹⁴⁵, but there was no such thing".¹⁴⁶ Allen's experiences reveal how difficult institutionalised life could be, and it suggests a system of care that is not designed to meet the needs of residents, but rather, is focused on segregation and social control. The institutional model of care for people who have disabilities is described as one that:

¹⁴² Thomas F Allen, Rannveig Traustadottir, and Lisa Spina, "Sixty Years in the Institution," in *Deinstitutionalization and People with Intellectual Disabilities* (London: Jessica Kingsley Press, 2005). P. 35.

¹⁴³ Allen, Traustadottir, and Lisa Spina. P. 41.

¹⁴⁴ Allen, Traustadottir, and Lisa Spina. P. 40-41.

¹⁴⁵ Referring to the Rome State School in New York State.

¹⁴⁶ Allen, Traustadottir, and Lisa Spina, "Sixty Years in the Institution." P. 40-41.

Denies choice, denies opportunity, that congregates, segregates and isolates people. ...Institutions deny you a life – they take away your ability to know and connect with your family – your community – deny you the opportunity for friendships. Institutions take away the ability to have responsibility for your own actions. An institution is a place where people are not permitted to dream.¹⁴⁷

Due to their lack of agency, institutionalised residents, such as Tom Allen, are believed by many to have been treated as non-persons. Not only were they hidden away from view, but there is substantial evidence that poor treatment was widespread. A well-publicised example of unacceptably poor treatment concerned the conditions of the Willowbrook State School, which was a New York State institutional facility used to house people who had intellectual disability. In 1972, investigative journalist Geraldo Rivera snuck into Willowbrook State School and filmed the disturbing condition of the residents. Rivera's expose was considered instrumental in changing: "[t]he face of mental health as we know it".¹⁴⁸ This is because the situation within Willowbrook was so distressing that it could not be ignored. Describing what he saw, Rivera stated:

The doctor had warned me that it would be bad. It was terrible. There was 1 attendant for perhaps 50 severely and profoundly retarded children. Laying on the floor naked and smeared with their own faeces, they were making a pitiful sound. The kind of mournful wail that it is impossible for me to forget. This is what it looked like, this is what it sounded like, but what can I tell you about how it smelled? It smelled of filth, it smelled of disease, it smelled of death.¹⁴⁹

Rivera's shock at what he saw was coupled with film footage that proved his words were true. Children were indeed laying naked on the floor in their own faeces. Others wore backless hospital gowns, and while some children were sitting in chairs, the film revealed there was not

¹⁴⁷ People First of Canada, "From Vision to Action -- Building and Inclusive and Accessible Canada: A National Action Plan on Disability" (Institution Watch.ca, 2007), <http://www.institutionwatch.ca>.

¹⁴⁸ Metrofocus, *The Story That Revealed Willowbrook's Horrors* (United States: PBS, 2016), <https://www.pbs.org/video/metrofocus-story-revealed-willowbrooks-horrors/>.

¹⁴⁹ Metrofocus.

enough furniture to accommodate those who may have wished to utilise it. Horrifically, these institutionalised children appeared remarkably thin, and the viewers' suspicion of starvation was confirmed when it was revealed that many of the children could not feed themselves and that staff could only afford a mere 3 minutes of time to feed each child. The medical doctor who cared for these children further admitted that the consequences of the 3 minute meals were: "[d]eath by pneumonia".¹⁵⁰ Arguably, it is this exact moment of investigative journalism that made Geraldo Rivera's career, but nearly 50 years on, he remains visibly shaken when speaking of the experience. With tears, Rivera describes the impact on himself:

You know I see that and it chokes me up to this day. It is almost like an automatic response. It just evokes—and I hadn't seen it in a while—it just evokes that original sensation. That feeling that I had when I walked in there with no—I had no connection at all to the population we used to define as mentally retarded--now developmentally disabled. So, seeing it for the first time it was like a traumatic shock. It was like—I hear described how G.I.s reacted when they saw the concentration camps when they were liberated. Even those who intellectually knew what they were getting into. It is like a post-traumatic stress almost. ...For a long time, I lived with the guilty feeling that my life had changed far more than their lives—the lives of the residents of Willowbrook—because I became a star. I became like the go-to boy of the city and for the under-privileged—and it really was—you know you had to live up to it—and that kind of fame is fleeting, but it was definitely a shockingly profound difference in my personal life.¹⁵¹

While Geraldo Rivera's expose of Willowbrook made him famous, this is not why his work is viewed as important to the social movement for de-institutionalisation. Other people, with much higher profiles and clout than Rivera, had attempted to draw public attention to Willowbrook, but had failed to ignite widespread outrage over the conditions. For example, New York Senator Robert Kennedy visited Willowbrook State School in 1965 and apparently

¹⁵⁰ Geraldo Rivera, *Willowbrook: The Last Great Disgrace* (United States: ABC News, 1972), <https://www.youtube.com/watch?v=xPvQpWEdxoY>.

¹⁵¹ Metrofocus, *The Story That Revealed Willowbrook's Horrors*.

witnessed the same conditions reported by Rivera. Kennedy described what he saw at Willowbrook in the starkest of terms:

I think at the state institution for the mentally retarded, and I think that particularly at Willowbrook, we have a situation that borders on a snake pit, and that the children live in filth, that many of our fellow citizens are suffering tremendously because of lack of attention, lack of imagination, lack of adequate manpower. There is very little future for these children, or for those who are in these institutions. Both need a tremendous overhauling. I'm not saying that those who are the attendants there, or ones who run the institutions, are at fault – I think all of us are at fault and I think it's long overdue that something be done about it.¹⁵²

Despite Kennedy's call to action, poor conditions continued at Willowbrook. Rivera attributes the lack of public attention to the lack of photographic evidence available.¹⁵³ Due to the right to privacy for institutionalised people, cameras were never permitted during tours of institutional facilities by journalists or officials. Thus, conditions could be described, but reasonably denied by governments.¹⁵⁴ Rivera did something that others before him had hesitated to do. Without permission, Rivera secretly entered the Willowbrook State School and filmed the residents and the conditions they suffered.¹⁵⁵ Returning various times, Rivera would appear at unexpected times at different state facilities, sometimes with politicians in tow, and sometimes with advocates for de-institutionalisation. The result was not simply footage of a single ward at Willowbrook, but extensive footage of many different buildings and interviews with both residents and staff.¹⁵⁶ When the evidence was broadcast on a national television network, the visual evidence was too horrifying to ignore.¹⁵⁷

¹⁵² Robert Kennedy, "Robert Kennedy Visiting Institutions in New York," *Parallels in Time: A History of Developmental Disability*, 2019, <https://mn.gov/mnddc/parallels/five/5b/bobby-kennedy-snakepits.html>.

¹⁵³ Metrofocus, *The Story That Revealed Willowbrook's Horrors*.

¹⁵⁴ Metrofocus.

¹⁵⁵ Rivera, *Willowbrook: The Last Great Disgrace*.

¹⁵⁶ Rivera.

¹⁵⁷ Metrofocus, *The Story That Revealed Willowbrook's Horrors*.

Rivera's investigative journalism portrayed a systemic neglect associated with underfunding. In one sequence Congressman Mario Biaggi asked a nurse at Letchworth Village Rehabilitation Centre why the patients were unclothed, and the nurse answered: "[w]e don't have enough clothing. We don't have the proper help to keep clothing on them. We have a few nudists that will not keep clothes on. They will pull them off—but most of all we do not have the help to keep them properly dressed. There are days we only have 4 or 5 attendants to take care of a hundred patients".¹⁵⁸ Congressman Biaggi, expressing disdain for what he saw, stated that the patients were living in: "[t]he worst possible conditions I've ever seen in my life. I've visited penal institutions all over the country. I've visited hospitals all over the country. I've visited the worst brigs in the military. I've never seen anything like this".¹⁵⁹ Ultimately, the staffing shortages were attributed to funding cuts that had resulted in a loss of 900 employees at Willowbrook and another 300 employees at Letchworth since 1970.¹⁶⁰

Understaffing is often accompanied with neglect of building maintenance. Institutional facilities have been discovered to be physically unsafe in many circumstances. For instance, there was a coroner's inquest in Australia after nine institutionalised men who had intellectual disabilities died by fire in 1996. Authorities were concerned as a very similar fire had occurred in the same facility in 1968, which had resulted in the deaths of six residents.¹⁶¹ The 1996 inquest concluded that various systemic and mechanical failures of the facility were responsible for the men's deaths, such as the start of the fire itself by an unsupervised resident; a lack of an effective alarm system; a non-operational sprinkler system; and the subsequent delayed

¹⁵⁸ Rivera, *Willowbrook: The Last Great Disgrace*.

¹⁵⁹ Rivera.

¹⁶⁰ Rivera.

¹⁶¹ Ian Freckleton, "Institutional Death: The Coronial Inquest into the Deaths of Nine Men with Intellectual Disabilities," in *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*, ed. Kelley Johnson and Ranveig Traustadottir (London: Jessica Kingsley Press, 2005). P. 83.

intervention of the fire brigade.¹⁶² Furthermore, the government had been given, but had chosen not to act upon many warnings by consultants and different government bodies that the facility required upgrading to ensure safety standards would be met.¹⁶³

Stigmatisation of the Institutionalised:

Neglecting institutional facilities and the institutionalised people within them appear to have a function. It is believed by many people that institutional facilities were designed to stigmatise the institutionalised.¹⁶⁴ The purpose of this stigmatisation is rooted in social control. In order to discourage people from seeking public assistance, the asylums and other institutional facilities stood as terrible places that were characterised by neglect.¹⁶⁵ If one failed to financially support themselves, failed to conform to mainstream social norms, had a disability, or was simply discarded by their family, they were liable to become institutionalised and forever stigmatised as a category of deficient persons. Ultimately, institutionalisation could be a consequence of unemployment, poverty, and mental disorder, all symptoms that were once thought to be associated with moral laxity.

Throughout Europe, governments long had an informal practice of demanding that the poor wear a sign to indicate to their community that they received some form of welfare.¹⁶⁶ In 1697, however, the custom of ‘badging the poor’ became law in England, and anyone found providing relief to unbadged beggars would be subject to a fine.¹⁶⁷ In the beginning, long before they became a requirement of the law, these badges functioned as: “[a] stamp of approval, a

¹⁶² Freckleton. P. 79.

¹⁶³ Freckleton. P. 81.

¹⁶⁴ Means, Richards, and Smith, *Community Care*. P. 43.

¹⁶⁵ Means, Richards, and Smith.

¹⁶⁶ Steve Hindle, “Dependency, Shame and Belonging: Badging the Deserving Poor, c.1550-1750,” *Cultural and Social History* 1, no. 1 (2004): 6–35. P. 6.

¹⁶⁷ Hindle. P. 6.

testimony of the truth of deserving or diseased status of those who wore them”.¹⁶⁸ By the mid-17th century, some of the population had started to criticise the badged poor for what they perceived as being: “[t]oo enthusiastic in claiming relief”.¹⁶⁹ Importantly, the act of wearing the pauper’s badge indicated to all that the wearer had satisfied all tests of worthiness demanded by the Parish and were deserving of relief.¹⁷⁰

In advance of the amendment to the Poor Law, Member of Parliament Lawrence Alcock argued that: “[b]adges seemed right ordered to be fixed as some public marks of shame, and to distinguish parish paupers from those industrious poor that live by their own endeavours”.¹⁷¹ Further arguments from other Members of Parliament asserted that only the poor that were unable to engage in labour, such as elderly widows and people who have disability, should be allowed to wear the badge as a license to beg.¹⁷² Still others argued that children, the sick, and the elderly should be exempt from badging so as not to shame them.¹⁷³ After the 1697 legislation was enacted, people that failed to wear a pauper badge had their relief discontinued, and it was possible to receive a prison term for refusing to wear the badge.¹⁷⁴ Even within small villages, where a limited number of people were recognised as worthy beggars and that were already well known to the community, the wearing of the pauper badge was enforced, with many parishes spending substantial sums on the manufacture of these badges.¹⁷⁵ Throughout the 18th

¹⁶⁸ Hindle. P. 7.

¹⁶⁹ Hindle. P. 11.

¹⁷⁰ Hindle. P. 25.

¹⁷¹ Hindle. P. 12.

¹⁷² Hindle. P. 12-18.

¹⁷³ Hindle. P. 17.

¹⁷⁴ Hindle. P. 17, 23.

¹⁷⁵ Hindle. P. 21

Century, badging became associated with the shame of needing public assistance, but numerous parishes continued to demand badging of the poor until 1810 when the practice was abolished.¹⁷⁶

Despite the stigmatisation and shaming of the poor, their numbers did not decrease, and many people refused to wear the pauper's badge. Those who did accept the pauper's badge in return for relief were at risk of having the Parish take control of their children, who would also be expected to wear the badge.¹⁷⁷ If the Parish chose, the children would be removed from the home and sent to work.¹⁷⁸ Thus, as some politicians had hoped, many poor people were discouraged from seeking welfare relief as the price for doing so was perceived to be too high.¹⁷⁹ Additionally, once people sought help from the government, the relief very often offered was entrance to a 'house of correction'.

Michel Foucault described how the governments of 16th and 17th century Europe launched a war upon the poor, confining as many possible to 'houses of correction', which were the precursors to the institutional facilities that took shape during the late 19th and early 20th centuries. Explaining the origins of the *Hôpital Général* in Paris, Foucault states:

From the beginning, the institution itself set itself the task of preventing "mendicancy and idleness as the source of all disorders". In fact, this was the last of the great measures that had been taken since the Renaissance to put an end to unemployment or at least to begging. In 1532 the *Parlement* of Paris decided to arrest beggars and force them to work in the sewers of the city, chained in pairs. ...on March 23rd, 1534, the order was given "to poor scholars and indigents" to leave the city, while it was forbidden "henceforth to sing hymns before images in the streets". The wars of religion multiplied this suspect crowd, which included peasants driven from their farms, disbanded soldiers or deserters, unemployed workers, impoverished students, and the sick. When Henri IV began the siege of

¹⁷⁶ Peter Higginbotham, "The History of Poor Law Unions," The Workhouse, 2019, <http://www.workhouses.org.uk/>.

¹⁷⁷ Hindle, "Dependency, Shame and Belonging: Badging the Deserving Poor, c.1550-1750."

¹⁷⁸ Hindle. P. 28.

¹⁷⁹ Hindle.

Paris, the city, which had less than 100,000 inhabitants, contained more than 30,000 beggars.¹⁸⁰

The problem of the impoverished masses of Paris became so severe that in 1606, *Parlement* decreed that beggars should be whipped in the public square, have their heads shorn, their shoulders branded, and be driven from the city.¹⁸¹ By 1607, archers were stationed at the city gates to thwart the entrance of indigents.¹⁸² Following labour uprisings across France, the *Hôpital Général* was opened in 1656, which served to become:

a new solution... the unemployed person was no longer driven away or punished; he was taken in charge, at the expense of the nation, but at the cost of his personal liberty. Between him and society, an implicit system of obligation was established; he had the right to be fed, but he must accept the physical and moral constraint of confinement.¹⁸³

Soon after the opening of the *Hôpital Général*, the militia: “[b]egan to hunt down beggars and herd them into different buildings of the *Hôpital*.”¹⁸⁴ In similar policy, England, which had also been opening ‘houses of correction’, had begun to transport their impoverished populations to Newfoundland and the West and East Indies.¹⁸⁵ The English attitude toward the poor was oriented toward a policy of punishment for the perceived lack of moral fitness that inevitably led to poverty. In 1630, the government issued statements claiming that the poor: “[l]ive like savages without being married, nor buried, nor baptised; and it is this licentious liberty which causes so many to rejoice in vagabondage”.¹⁸⁶ During the same period the Lord Mayor of London complained the poor were a: “[v]ermin that troops about the city, disturbing public

¹⁸⁰ Michel Foucault, *Madness and Civilisation: A History of Insanity in the Age of Reason* (New York City: Random House, 1965). P. 47.

¹⁸¹ Foucault. P. 47.

¹⁸² Foucault. P. 47.

¹⁸³ Foucault. P. 48.

¹⁸⁴ Foucault. P. 49.

¹⁸⁵ Foucault. P. 50.

¹⁸⁶ Foucault. P. 50.

order, assaulting carriages, demanding alms with loud cries at the doors of churches and private houses”.¹⁸⁷

The impoverished population of English people had grown from the impacts of the enclosure movement and the industrial revolution. Karl Polanyi described the enclosure movement as:

a revolution of the rich against the poor. The Lords and nobles were upsetting the social order, breaking down ancient law and custom, sometimes by means of violence, often by pressure and intimidation. They were literally robbing the poor of their share of the common, tearing down the houses which, by the hitherto unbreakable force of custom, the poor had long regarded as theirs and their heirs. The fabric of society was being disrupted; desolate villages and the ruins of human dwellings testified to the fierceness with which the revolution raged, endangering the defences of the country, wasting its towns, decimating its population, turning its overburdened soil into dust, harassing its people and turning them from decent husbandmen into a mob of beggars and thieves.¹⁸⁸

Later, with the advent of the Industrial Revolution, pressures upon the working classes were increased further. Polanyi described that:

the labouring people had been crowded together in new places of desolation, the so-called industrial towns of England; the country folk had been dehumanised into slum dwellers; the family was on the road to perdition; and large parts of the country were rapidly disappearing under the slack and scrap heaps vomited forth from the “satanic mills”. Writers of all views and parties, conservatives and liberals, capitalists and socialists, invariably referred to social conditions under the Industrial Revolution as a veritable abyss of human degradation.¹⁸⁹

In the hope of mitigating the problem, the poor were sent to ‘workhouses’, where they would be ‘reformed’ and put to work. All over Europe, confined paupers traded their labour in return for their room and board.¹⁹⁰ In England, private manufacturers, however, did not wish to

¹⁸⁷ Foucault. P. 50.

¹⁸⁸ Karl Polanyi, *The Great Transformation: The Political and Economic Origins of Our Time*, Second Beacon Paperback Edition (Boston: Beacon Press, 2001). P. 37.

¹⁸⁹ Polanyi. P. 41.

¹⁹⁰ Foucault, *Madness and Civilisation: A History of Insanity in the Age of Reason*. P. 52.

compete with the workhouses, and the ability to provide workhouse labour to the market was constrained as it was creating further unemployment. This resulted in the confined poor being unable to pay for their upkeep and being transferred to prisons.¹⁹¹ In France, partnerships between private manufacturers and hospitals were established, dividing profits between the manufacturers and the hospitals.¹⁹²

In 1834, there was a perceived need to amend the Poor Law, which allowed parishes in England and Wales to create Poor Law Unions. The Poor Law Unions served to centralise and routinise the disjointed systems of welfare that were overseen by individual parishes.¹⁹³ The foundation of this new standardised system was to be the workhouse.¹⁹⁴ By 1839, 583 unions were operating in England and Wales, and their workhouses became the only source of relief for abled-bodied poor people.¹⁹⁵ The workhouse model of dealing with the poor was evidently admired by many nations as similar institutional facilities were established in Japan, Scandinavia, Germany, Belgium, France, Portugal, Mexico, the United States, and Canada.¹⁹⁶ Canada, as part of the British Empire, opened several workhouses during the 19th Century.¹⁹⁷

The workhouses confined people who had various disabilities, and some of them were specifically designed to accommodate those people who were poor due to illness.¹⁹⁸ Still, it became the norm to mix the old and sick with ‘able-bodied paupers’, with their only common characteristic being that they were unable to support themselves financially. A 1797 government report describes the population of the Leeds Workhouse: “[t]here are 154 inmates in the

¹⁹¹ Foucault. P.52.

¹⁹² Foucault. P. 53.

¹⁹³ Peter Higgenbotham, “The Poor Laws,” The Workhouse, 2019, <http://www.workhouses.org.uk/poorlaws/>.

¹⁹⁴ Higgenbotham.

¹⁹⁵ Higgenbotham, “The History of Poor Law Unions.”

¹⁹⁶ Higgenbotham.

¹⁹⁷ Higgenbotham.

¹⁹⁸ Higgenbotham.

Workhouse, of whom 42 are old and infirm men or lunatics, 56 women, many of them soldier's wives, and 56 children mostly under 12. There are a few cripples or idiots between 12 and 20. Children are generally bound apprentices at 9 or 10".¹⁹⁹ During this same period, eager entrepreneurs could "farm the poor" by receiving contracts from the parishes to deliver welfare services.²⁰⁰ This early example of a welfare market offered contracts with terms that allowed entrepreneurs to develop for-profit enterprises:

The contractor is allowed the use of the house and furniture, and the earnings of the Poor, and receives £1,000 a year for which he is bound to maintain the Poor of every description, but not bear the expense of removals, appeals, or other law contests. There are at present (October 1795) 124 inmates, of whom 50 are old and infirm, and generally about the same in Winter. There are a few out-pensioners, but the payments are very trifling, as it is more for the interest of the contractor to offer the Poor who apply for relief no alternative but the house. The infirm who can work are employed in picking wool, the children attend the carding machine, spin, etc., and are taught to read twice a day. Boys and girls, men and women sleep in different quarters of the house. The contractor says he keeps no account of expenses or earnings.²⁰¹

Welfare services for people who have disabilities did not appear to improve for more than 100 years. In 1904, there was a 'Royal Commission on Mental Deficiency' that concluded that all 'mental defectives' should be exempt from the Poor Law.²⁰² A contemporary read of the reports of this commission reveal not only that conditions for people who had intellectual disabilities were horrific, but that attitudes toward people who had intellectual disabilities lacked recognition of their humanity. Describing the conditions within the workhouses, the commissioners stated:

¹⁹⁹ Higgenbotham.

²⁰⁰ Higgenbotham, "The Poor Laws."

²⁰¹ Higgenbotham.

²⁰² Kathleen Woodroffe, "The Royal Commission on the Poor Laws 1905-09," *International Review of Social History* 22, no. 2 (1977), https://www.cambridge.org/core/services/aop-cambridge-core/content/view/536EA4779184961716587EA2370854C8/S0020859000005472a.pdf/royal_commission_on_the_poor_laws_190509.pdf. P.148.

We have seen feeble-minded boys growing up in the Workhouse year after year untaught and untrained, alternately neglected and tormented by other inmates, because it had not occurred to the Board of Guardians to send them to (and to pay for them at) a suitable institution. We have ourselves seen – what one of the Local Government Board Inspectors describes as a common occurrence – ‘idiots who are physically offensive or mischievous, or so noisy as to create a disturbance by day and by night with their howls’, living in the ordinary wards, to the perpetual annoyance and disgust of the other inmates. We have seen imbeciles annoying the sane, and the sane tormenting the imbeciles. We have seen half-witted women nursing the sick, feeble-minded women in charge of the babies, and imbecile old men put to look after the boys out of school hours. We have seen expectant mothers, who have come in for their confinements, by day and by night working, eating, and sleeping in close companionship with idiots and imbeciles of revolting habits and hideous appearance.²⁰³

As many authors have noted, there was little differentiation allowed between those who were unable to financially support themselves due to infirmity and age, and the ‘able-bodied’ poor who simply could not find employment. Increasingly, many people’s attitudes toward the poor were less oriented to the idea that the poor were victims of their situation, which is a common interpretation of the Gospels, to a view that the poor were responsible for their own poverty.²⁰⁴ Unemployment became medicalised and promoted as a moral failure and a mental sickness that required treatment. Poverty and its impacts on the individual came to be viewed as mental illness and feeble-mindedness that was both the cause and result of immorality. Foucault described this ethic as: “[i]ndigence, laziness, vice, and madness mingled in an equal guilt within unreason. Now madness belonged to social failure, which appeared without distinction as its cause, model, and limit. ...mental disease would become degeneracy”.²⁰⁵

The willingness of governments to institutionalise impoverished moral ‘degenerates’ well into the 20th century confirms that medicalisation of morality and its relationship to poverty

²⁰³ Woodroffe. P. 148.

²⁰⁴ Higgenbotham, “The Poor Laws.”

²⁰⁵ Foucault, *Madness and Civilisation: A History of Insanity in the Age of Reason*. P 259.

persisted. Furthermore, the focus on poverty as the result of mental illness negatively influenced the form of treatment available to patients that truly did suffer from mental illness, subjecting them to confinement, hard labour, and stigmatisation associated with their condition. Even in 2019, many advocates for the inclusion of people who have disabilities assert that they must continue to deflect attitudes that embrace the idea that mental illness or intellectual disabilities are the result of character flaws or moral failings.

In 1929, the same year that the Weyburn Mental Hospital was opened in Saskatchewan, the British Government abolished the Poor Law Unions and created a new welfare system. Just the same, the workhouses continued to operate, and many institutional facilities that were labelled as mental hospitals and training schools would accept orphans, single mothers, unemployed men, and others that had difficulty with the local authorities. In the Canadian context, several training schools emerged in the mid-20th Century, 18 of which were located within Ontario, whose government is now subject to a \$600 million class-action suit alleging systematic state sanctioned abuse.²⁰⁶ The Ontario training schools had a mandate for dealing with ‘unmanageable children’, and had long institutionalised people who have intellectual disabilities in purpose designed facilities such as the Asylum for Idiots and Feeble-minded in Orillia that opened in 1876. In other provinces, such as Saskatchewan, the training school served as a facility to house people with intellectual disabilities, but also admitted children that were experiencing social problems. In Alberta, the Provincial Training School had a vague mandate of training the ‘mentally defective’ and was an important tool for Alberta’s eugenics board.²⁰⁷

²⁰⁶ Peter Akman, “‘It Felt like a Prison for Kids’: W5 Investigates Allegations of Abuse at Ontario Training Schools,” W5, March 8, 2019, <https://www.ctvnews.ca/w5/it-felt-like-a-prison-for-kids-w5-investigates-allegations-of-abuse-at-ontario-training-schools-1.4327718>.

²⁰⁷ Colette Leung, “Provincial Training School,” Eugenics Archive, 2019, <http://eugenicsarchive.ca/discover/institutions/map/517da50e9786fa0a73000001>.

Since the 1970s, there has been an effort by the governments of many Western nations to de-institutionalise people who have disabilities, and to close the institutional facilities that housed them. For example, there were 194, 650 institutionalised people who had intellectual disabilities in the United States in 1967. By 2004, this population had declined to 41, 653.²⁰⁸ The goal of de-institutionalisation, as understood by advocates for de-institutionalisation, is to transition all individuals to the community where they may participate in society as full citizens, and where they can attain independence and choices regarding their own lives. Advocates for de-institutionalisation refer to the ‘normalisation principle’, which argues that people who have intellectual disabilities should be treated in a normal way.²⁰⁹ This means that the normal patterns and conditions of everyday life should be made available to people who have disabilities.²¹⁰ Within this view, the way to achieve normal patterns and conditions of everyday life is through the closure of institutional facilities, and integrating people with disabilities into the community.

De-institutionalisation as a Social Movement:

The change in policy from institutionalisation to de-institutionalisation is the result of two key factors.²¹¹ The first factor is the successful influence of the social movement for de-institutionalisation that has advocated for the participation of people who have disabilities within society. The second factor is concerned with the high cost to governments for the provision of welfare services. Both factors have had an influence on how the project of de-institutionalisation has progressed. Before the policy of de-institutionalisation was adopted, the concept was first

²⁰⁸ Bonnie Shoultz, Pam Walker, and Steve Taylor, “Status of Institutional Closure Efforts in 2005,” ed. Research and Training Center on Community Living, *Policy Research Brief* (Minneapolis: College of Education and Human Development, University of Minnesota, 2005). P. 1.

²⁰⁹ Martha Thurlow et al., “Deinstitutionalization and Residential Services: A Literature Survey,” *Information and Technical Assistance Project on Deinstitutionalization* (Springfield, Virginia: United States Department of Commerce University of Minnesota, 1978). P. 2.

²¹⁰ Thurlow et al.

²¹¹ Shoultz, Walker, and Taylor, “Status of Institutional Closure Efforts in 2005.” P. 2.

constructed by advocates for people who have disabilities. As James March and Johan Oleson assert: “[a]ttention is a scarce good in politics”.²¹² These authors encourage awareness that lower status groups and social movements will have difficulty gaining attention and the advice of competent experts.²¹³ The long path toward success for the social movement for the de-institutionalisation of people who have intellectual disabilities was achieved through law courts and legislation that affirmed the human and civil rights of people who have disabilities.²¹⁴

During the 1970s, in the United States, the rights of people who have intellectual disability received a great deal of attention.²¹⁵ Part of the reason for this attention was due to the efforts of post-war social movements that advocated the extension of human rights to all individuals, rather than simply affording specific rights to minority groups.²¹⁶ The ethic of human rights for all promoted the right to education, medical treatment, community inclusion, due process, and equal protection for people who have intellectual disability, and advocates determined that these rights were guaranteed by the United States Constitution.²¹⁷ Still, mainstream acceptance of new ideas tends to take time. It was only through the legal recognition of these basic human and civil rights that the courts could reshape the American education system to include people who have intellectual disabilities, many of whom had long been discriminated against within schools and society at large. The problem of discriminatory attitudes toward people who have intellectual disability were well discussed within the academic literature. One author lamented that: “[h]uman rights in our society are not guaranteed or

²¹² James March and Johan Oleson, *Rediscovering Institutions: The Organizational Basis of Politics* (New York City: Free Press, 1989). P. 27.

²¹³ March and Oleson. P. 32.

²¹⁴ Thurlow et al., “Deinstitutionalization and Residential Services: A Literature Survey.” P. 69.

²¹⁵ Thurlow et al.

²¹⁶ Will Kymlicka, *Multicultural Citizenship: A Liberal Theory of Minority Rights* (Oxford: Oxford University Press, 1995). P.3.

²¹⁷ Thurlow et al., “Deinstitutionalization and Residential Services: A Literature Survey.” P. 70.

produced by good will alone. The fabric of our society, including many of its customs, is dictated, controlled, or modified by law. The mentally retarded, in spite of the pious protestations of good will, are still too often regarded as a sub-specie of *homosapiens*".²¹⁸

Changing policy required society to experience a paradigm shift in the acceptance of institutionalised discourses that dominated attitudes toward people who have disability. Michel Foucault wrote extensively about the roles of discourse in the development of policies and the administration of institutions, such as hospitals for the mentally ill.²¹⁹ Foucault's analysis emphasised how people's identities are constructed through discourses (systems of thought, beliefs, attitudes, and action), and that discourse functions to construct the rules and norms of a society at any given time.²²⁰ Institutionalised residents sometimes appear to have accepted the role of the institution in 'reforming' their character. One institutionalised British woman, for example, requested release after acknowledging that she had benefitted from over two decades of institutional care and control. Now, she asserted, she had the ability to care for herself.²²¹ The woman's attitude suggests that she had embraced the discourse of institutionalisation in that she believed that she had been a deficient person, unable to operate in society until she had become reformed. In the same manner, mainstream society had accepted the discourse that this woman was somehow deficient and required institutionalisation for the protection of society, and herself.

The discourses of institutionalisation are the constraints that hold institutionalised people within the boundaries of the institutional facility. As Foucault suggests, the discourses serve to legitimise the power of the State to institutionalise people. This power does not merely emanate

²¹⁸ Thurlow et al. P. 71.

²¹⁹ Frank Fischer, *Reframing Public Policy* (Oxford: Oxford University Press, 2002). P. 38.

²²⁰ Fischer. P. 38.

²²¹ Walmsley, "Institutionalization: A Historical Perspective." P.59.

from the State, but it is dispersed throughout all social relations.²²² Therefore, the process of de-institutionalisation must involve changing the ideas and attitudes of experts, but also changing the attitudes of the general population. This is done by re-constructing the discourses about how to care for care and how to include people who have intellectual disability. As described above, European attitudes toward people who have intellectual disabilities has produced social policies where people who have intellectual disabilities are segregated, confined, and believed to be a harm to the community.

Through the social movement for de-institutionalisation, re-constructing discourses has enabled significant progress in overturning the hegemonic policy of institutionalisation, and this policy no longer dominates our economic, ideological and cultural spheres. Yet, changing attitudes was an uphill battle. In the United States, the National Association of Superintendents of Public Residential Facilities declared in 1972 that successful de-institutionalisation depended on community support.²²³ This is because public ignorance about intellectual and developmental disabilities had fostered attitudes of indifference or antagonism, creating a barrier for inclusion.²²⁴ Since the public negatively viewed persons with intellectual and developmental disabilities, and it was widely assumed that intellectual disabilities were associated with emotional and social deviance, there was a need for a public education program in order to facilitate the de-institutionalisation process.²²⁵ Advocates for de-institutionalisation believed the need was urgent as: “[m]any people in the community are still superstitious and ignorant about the causes of mental retardation and the benefits of amelioration: They look upon retardation as a

²²² Fischer, *Reframing Public Policy*. P. 39.

²²³ Thurlow et al., “Deinstitutionalization and Residential Services: A Literature Survey.” P. 26.

²²⁴ Thurlow et al.

²²⁵ Thurlow et al. P. 27.

contagious disease which can be contracted. Efforts to educate the community must be continued”.²²⁶

Of these strategies to increase public awareness, the use of mass media was believed by advocates to be very effective due to its ability to reach the general public.²²⁷ Additionally, advocates believed that involving the receiving community in a de-institutionalisation plan had proven to motivate the community to embrace the inclusion of people who have intellectual disabilities.²²⁸ Ultimately, attitudes have gradually shifted in favour of de-institutionalisation and inclusion, and the United Nations Convention on the Rights of Persons with Disabilities (2006) has recognised the rights of individuals to receive: “[a] range of in-home, residential, and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”.²²⁹ This declaration of the United Nations reveals that global attitudes have shifted away from policies of institutionalisation.

The Rise and Fall of the Welfare State:

The provision of care for people who have intellectual disability has been intimately connected to the specific economic doctrines that governments embrace. Roger Stancliffe and Charlie Lakin assert that welfare service provision is guided by economic ideas.²³⁰ As observed in the above discussion concerning Western welfare policies that were developed between the 16th and 19th Centuries, it is clear that specific economic ideologies had influenced how

²²⁶ Thurlow et al. P. 28.

²²⁷ Thurlow et al. P. 30.

²²⁸ Thurlow et al.

²²⁹ Jim Mansell and Julie Beadle, “Deinstitutionalization and Community Living: Position Statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities,” *Journal of Intellectual Disability Research* 54, no. 2 (2010).

²³⁰ R J Stancliffe et al., “The Economics of Deinstitutionalization,” in *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, ed. R J Stancliffe and K Lakin (Baltimore: Brookes Publishing, 2005). P. 1.

vulnerable people were cared for by the state. Nearing the end of the 19th Century, however European attitudes toward the perennial problem of the poor began to be influenced by increasing social and economic change.²³¹ Not only did the developing Social Gospel movement strive to apply Christian principles to social problems, but labour movements were organising and calling for better work conditions.²³²

The rise of the modern welfare state is acknowledged as having begun in Germany with Otto von Bismarck, who implemented various welfare programs that would benefit workers, such as the Sickness Insurance law of 1883 and the Accident Insurance Law of 1884.²³³ Bismarck referred to these social reforms as ‘practical Christianity’ in a conscious attempt to accommodate the Church and emerging Christian Democrat political parties.²³⁴ Additionally, there was conflict between the Church and liberal governments, each demanding jurisdiction over the amelioration of social problems.²³⁵ Thus, governments seeking to secularise or maintain a separation of Church and State found themselves implementing social programs that were demanded by religious groups. These, however, are only a few of the factors that are attributed to the rise of Western welfare states. Possible contributing factors are endlessly advanced, but a contemporary historical view interprets the period between 1870 and 1914 as the ‘first era of globalisation’, where states determined that the provision of accommodations to the working class was necessary to remain competitive.²³⁶

²³¹ Francis Castles et al., *Oxford Handbook of the Welfare State* (Oxford: Oxford University Press, 2010), <https://books.google.ca/books?id=ILawRZJhlqAC&printsec=frontcover&dq=isbn:9780199579396&hl=en&sa=X&ved=0ahUKEwiSgb23943mAhVLPZ4KH2yAOIQ6AEIKTAA#v=onepage&q&f=false>.

²³² Castles et al.

²³³ Howard Leichter, *A Comparative Approach to Policy Analysis: Healthcare Policy in Four Nations* (Cambridge: Cambridge University Press, 1979). P. 3.

²³⁴ Castles et al., *Oxford Handbook of the Welfare State*. P. 66.

²³⁵ Castles et al. P. 4.

²³⁶ Castles et al. P. 5.

State welfare programs for workers came slightly later to Britain than they had to the European continent. In 1909, the government introduced the Old Age Pension, and in 1911, limited forms of unemployment insurance and health insurance were enacted.²³⁷ In 1916, a pension system was developed for disabled World War I veterans and their widows.²³⁸ These provisions would have served to keep many of the elderly, the sick, disabled veterans, and their dependents out of the workhouses and in more independent situations. Although still closely associated with Britain, Canada did not develop similar social security programs until much later, establishing the Old Age Pension in 1927 and Unemployment Insurance in 1940.²³⁹

The impacts from World War I and the global economic disaster beginning in 1929 necessitated that Western governments develop social programs to assist the growing masses of impoverished people. The Great Depression, as described by Karl Polanyi, had resulted from the cataclysmic failure of the *laissez-faire* capitalism that defined the self-regulating market economy of the 19th century.²⁴⁰ The social policy of this 'economic liberalism' had emphasised a crude utilitarianism, where the market was expected to sort out the plight of the poor, but the ill effects of high unemployment and extreme poverty that occurred during the Great Depression had become excessively severe.²⁴¹ Attitudes began to shift away from *laissez-faire* capitalism, and toward the social safety net promised by the Welfare State.²⁴² The Welfare State brought many benefits to people who have disabilities, but many of these benefits were delivered only through institutionalisation. Some advocates for the social movement for de-institutionalisation

²³⁷ Higgenbotham, "The Poor Laws."

²³⁸ Janis Lomas, "Soldiering On: War Widows in First World War Britain," in *The Home Front in Britain* (London: Palgrave Macmillan, 2014).

²³⁹ Castles et al., *Oxford Handbook of the Welfare State*. P. 71.

²⁴⁰ Polanyi, *The Great Transformation: The Political and Economic Origins of Our Time*. P. 30.

²⁴¹ Polanyi. P. 117.

²⁴² Keith Brown, *Vulnerable Adults and Community Care* (Exeter: Learning Matters, 2006). P. 3.

associate the ‘Welfare State’ with institutionalisation²⁴³, even though the policy of institutionalisation predates the rise of the modern Welfare State. This attitude is due to the power and control that the Welfare State is perceived to assert over people who have disabilities.

There are varying definitions of what a ‘Welfare State’ is.²⁴⁴ Within the context of this argument, the ‘Welfare State’ is described as the economic system of ‘welfare capitalism’ that became dominant in Western democracies following World War II. Welfare capitalism may also be referred to as a ‘Keynesian Welfare State’.²⁴⁵ Keynesian economic ideology directed British policy between 1945 and 1980 when the government chose a new economic direction.²⁴⁶ Many different nations adopted Keynesian economic ideology during the same period, Canada being one of these.²⁴⁷ Seeking to supply all citizens of a nation with the ability to fully participate socially and economically within society, the economic goals of welfare capitalism are achieved through the presence of a mixed-economy (both a public and a private sector), commitment to regulation of the economy through Keynesian fiscal and monetary control, state financed provision of welfare, and the promotion of trade unionism.²⁴⁸ Advocates for welfare capitalism believe that provision of payments to the old, sick, disabled, and unemployed, while also supplying universal healthcare and education to all members of society will reduce the negative impacts of unemployment and poverty.²⁴⁹ During this Keynesian era, the population of institutionalised people expanded, as governments had accepted responsibility for the care of people who have disability.

²⁴³ The Stakeholders, “Interview Data.”

²⁴⁴ Greve, *Historical Dictionary of the Welfare State*.

²⁴⁵ Brown, *Vulnerable Adults and Community Care*. P. 1.

²⁴⁶ Brown. P. 2.

²⁴⁷ Brown. P. 2.

²⁴⁸ Brown. P. 2.

²⁴⁹ Brown. P. 2.

During the 1970s, a severe and global economic recession occurred, which led to renewed interest in 'free-market thinking'.²⁵⁰ As a result of this recession, governments became determined to replace Keynesian policies with monetarism, which favours a more *laissez-faire* approach to markets. This paradigm shift in economic policy was beneficial to the social movement for de-institutionalisation as monetarist theories are complimentary to the idea of closing state run institutional facilities and reducing state responsibility for providing the practical elements of care for people who have disabilities. As adherents of monetarism, both Margaret Thatcher and Ronald Reagan called for a reduction of public spending and limiting the role of the state in the economy.²⁵¹ Many nations chose to follow the lead of Britain and the United States and adopted monetarism. Since policies of institutionalisation are costly, advocates of the new paradigm generally supported the request to switch resources from institutional care, to community care.²⁵²

In her own words, Margaret Thatcher described the reasons why she worked to limit her government's role and pursued privatisation of state owned interests: "[t]he evidence of the lamentable performance of government in running any business – or indeed administering any service – is so overwhelming that the onus should always be on statist to demonstrate why government should perform a particular function rather than why the private sector should not".²⁵³ Thatcher's sentiment extended to health care and state owned hospitals, but privatisation of healthcare demanded the availability of a health care market. New de-institutionalisation friendly policies were developed, and the government decided that: "[t]he provision and

²⁵⁰ Brown. P. 6.

²⁵¹ Peter Hall, "Policy Paradigms, Social Learning and the State: The Case of Economic Policy-Making in Britain," *Comparative Politics* 25, no. 3 (1993). P.286.

²⁵² Means, Richards, and Smith, *Community Care*. P. 44.

²⁵³ Margaret Thatcher, *The Downing Street Years* (New York City: HarperCollins Publishers Inc., 1993). P.677.

financing of health care were to be separated, with money following the patient”.²⁵⁴ Thus, the government would continue to fund the health care needs of vulnerable people, but the patient would now would have the ability to choose service providers from within a regulated health care market.

Thatcher believed that her government’s privatisation policies were “[o]ne of Britain’s most successful exports” that had: “[r]e-established our reputation as a nation of innovators and entrepreneurs”.²⁵⁵ There is truth in this as many nations have and continue to adopt monetarist and privatisation policies. Keith Banting and John Myles refer to this drawing down of the ‘Welfare State’ that is occurring within many advanced Western democracies as 're-distributive fade' resulting from the pressures of globalisation, rapid technological change, and the emergence of new forms of families.²⁵⁶ Canada, in particular, embarked on a program change in the way welfare services were designed and delivered.

Between 1985 and 1995, the Organization for Economic Cooperation and Development described Canada, Denmark, Finland and Sweden as being the nations whose re-distributive policies produced the smallest gap between rich and poor.²⁵⁷ By 2005, however, Canada had joined Switzerland and the United States as the nations whose re-distributive policies had the lowest impact.²⁵⁸ Reasons given for the rise in inequality is empirically explained by the rise in market incomes and investments that began in the early 1980s.²⁵⁹ Until 1994, transfers and taxes were able to compensate for this dramatic rise in market incomes and investments, but mid-

²⁵⁴ Thatcher. P. 616.

²⁵⁵ Thatcher. P. 686.

²⁵⁶ Keith Banting and John Myles, *Inequality and the Fading of Re-Distributive Politics* (Vancouver: UBC Press, 2013). P. 1.

²⁵⁷ Banting and Myles. P. 2.

²⁵⁸ Banting and Myles. P. 511.

²⁵⁹ Banting and Myles. P 511-512.

1990s reforms to programs such as Employment Insurance, Social Assistance, and the tax and transfer system made it impossible to continue offsetting the rise.²⁶⁰

Cuts to Canadian social programs were influenced by the embrace of monetarism, but also through the changing political narratives concerning poverty and the poor. After World War II, there arose an affluent working class that was no longer identifiable as the same group of people that the British Poor Laws had described.²⁶¹ Canada's Unemployment Insurance, Old Age Pension, and health insurance were universal and benefitted the whole of the population without making distinctions between the 'worthy poor' and the undeserving. The result of these universal programs was that social services benefitted all Canadians, not just the impoverished, although these programs did tend to help the poorest Canadians the most.²⁶² Additionally, the population as a whole was served in terms of education and health care, and had the added benefit of fostering unity amongst diverse regions of the country.²⁶³ The Canadian social programs appear to have functioned so well that the working class was no longer poor. Instead, definitions of poverty were oriented towards those who were experiencing the deepest social problems. Turning away from ideas of universality that benefitted the whole population, policies increasingly targeted the most impoverished of the population, and only the most deserving of the impoverished population. This sentiment was manifest in the increasing demand for income testing possible welfare recipients.²⁶⁴

The cuts to welfare programs in Canada have had a negative consequence for people who have disabilities. Often perceived to be amongst the 'Worthy Poor', people who have disabilities

²⁶⁰ Banting and Myles. P. 511-512.

²⁶¹ Banting and Myles. P. 517.

²⁶² Banting and Myles. P. 517.

²⁶³ Banting and Myles. P. 518.

²⁶⁴ Banting and Myles. P. 518.

comprise three-quarters of low income welfare recipients in Canada, and people who have intellectual and psychiatric disabilities are additionally likely to receive social services.²⁶⁵ Yet, between 1994 and 2006, the value of disability benefits have declined by almost 14%.²⁶⁶ In 1994, the average yearly disability social assistance benefit was \$11, 675, but by 2006 it had declined to \$10, 056, with Saskatchewan citizens averaging only \$9, 860 in social assistance benefits.²⁶⁷

Proponents of free markets subscribe to the idea that state welfare inhibits commerce due to excessive tax demands, and because the State becomes a monopoly supplier of welfare goods.²⁶⁸ As well, free market advocates tend to believe that welfare programs will create dependency upon the State by undermining the family and the ability of individuals to take personal responsibility for their lives.²⁶⁹ Instead, free market advocates prescribe a supply of welfare services that are competitive, privately owned, and are ideally purchased by unsubsidised individuals.²⁷⁰ These types of welfare policies are complimentary to many of the goals of de-institutionalisation. For example, advocates for de-institutionalisation desire that welfare consumers should be able to opt out of state provision of services, that individual choice is necessary, and that individuals should never be served in institutions, but rather by their own families or a contracted caregiver of their choosing.²⁷¹ After the conversion to monetarist principles, the Thatcher/Major government reduced public spending on welfare services, created health care markets, and transferred the responsibility of care to consumers and welfare

²⁶⁵ Michael Prince, "Entrenched Residualism," in *Welfare Reform in Canada: Provincial Social Assistance in Comparative Perspective*, ed. Daniel Beland and Pierre-Marc Daigneault (Toronto: University of Toronto Press, 2015). P. 296.

²⁶⁶ Prince. P. 297.

²⁶⁷ Prince. P. 297.

²⁶⁸ Brown, *Vulnerable Adults and Community Care*. P. 12.

²⁶⁹ Brown. P. 12.

²⁷⁰ Brown. P. 12.

²⁷¹ Brown. P. 12.

managers, which generally pleased advocates for de-institutionalisation. Still, while governments have become amenable to the idea of closing state-run institutional facilities, advocates for de-institutionalisation have continued to strive for governments to invest in social services.

De-institutionalisation as De-construction of the Welfare State:

In 1988, the Conservative government of the United Kingdom commissioned Sir Roy Griffiths to create a strategy for community care. The result was Griffiths' report entitled "Community Care: An Agenda for Reform".²⁷² In keeping with the government's decision to adhere to free market values, Griffiths designed a system of care that required the development of 'welfare markets'.²⁷³ Welfare markets are defined as "[c]ompetitive spheres in the provision of social welfare."²⁷⁴ The goal of welfare markets is to encourage welfare recipients to rely on services offered through the private labour market, which allows governments to 'privatise' welfare provision and reduce the costs of care provision.²⁷⁵

De-construction of the Welfare State has been an important goal of governments that are pursuing monetarist policies, and it is important to understand that de-institutionalisation through privatisation was designed to relieve the government as the monopolistic provider of welfare services. Many nations, including Canada, have adopted Britain's example of welfare markets to reform their economies. A common strategy to replace public care with private care is through providing tax credits, or public subsidies, to those citizens who take steps to mitigate their own social risks.²⁷⁶ For example, Canada provides a Registered Disability Savings Plan (RDSP),

²⁷² Means, Richards, and Smith, *Community Care*. P. 52.

²⁷³ Means, Richards, and Smith.

²⁷⁴ Ingo Bode, *The Culture of Welfare Markets: The International Recasting of Pension and Care Systems* (New York: Routledge, 2008). P. 15.

²⁷⁵ Bode. P. 15.

²⁷⁶ Bode.

where the government provides matching grants of up to 300% of personal contributions.²⁷⁷

Strategies such as this provide less financially vulnerable persons with disabilities to limit their reliance on the state, and this goal is complementary to the new economic paradigm.

Reduction in spending and the creation of financial incentives did not alone create the desired welfare market. Instead, true marketisation of welfare was achieved in Britain through the development of quasi-autonomous non-governmental organisations (quangos).²⁷⁸ A quango, for example, will offer competitive contracts to independent (private) businesses that offer care services for profit.²⁷⁹ In general, contracts with service suppliers are fixed term and based on various modes of remuneration, such as per capita reimbursement, capped block grants and performance related payment.²⁸⁰ In order to allow this model of care provision to work, financial responsibility for care must be de-centralised, and new bureaucratic care management roles must be constructed.²⁸¹ For example, quangos, when serving as care managers, will define a range of services that are available for care receivers to purchase, using funds that are provided from their personal allowances.²⁸² The quango is meant to serve as a de-centralised and privatised substitute for the government, thus reducing the reach of the State.

In Canada, the system is slightly different, with each individual province responsible for their own provision of welfare services. In Saskatchewan, for example, community-based organisations (CBOs), which tend to be not-for-profit entities, receive contracts directly from the Ministry of Social Services to provide care for vulnerable persons. The Ministry of Social

²⁷⁷ Employment and Social Development Canada, "Registered Disability Savings Plan" (Government of Canada, 2014), <http://www.esdc.gc.ca/eng/disability/savings/index.shtml>.

²⁷⁸ Bode, *The Culture of Welfare Markets: The International Recasting of Pension and Care Systems*. P. 16.

²⁷⁹ Bode. P. 16.

²⁸⁰ Bode. P. 16.

²⁸¹ Bode.P. 16.

²⁸² Bode. P. 18.

Services also provides funding to independent community-based organisations to provide advocacy for vulnerable persons, and to assist care receivers and their families with managing care. Currently, Inclusion Saskatchewan acts as the main advocate for people who have intellectual disability. Additionally, Saskatchewan allows for self-directed funding so that people who have intellectual disabilities may choose which welfare services best fit their needs.

Welfare Markets were a radical invention that allowed the British Government to reduce public expenditures on care for people who have disabilities.²⁸³ As the arranger and purchaser of welfare, the quangos would be responsible for the assessment of individuals, determination of what services were needed, design of service packages, and contracting the service providers; thus designing care to meet the needs of people.²⁸⁴ Designing care to fit people is thought to be more efficient than a one-size-fits-all form of provision.²⁸⁵ Through the use of quangos, the responsibility of care for vulnerable people became de-centralised from state to regional authorities through the transfer of funds from the Social Security budget, with regional authorities then able to choose how they would deliver care.²⁸⁶ In order to administrate this new architecture of care, Griffiths called for the creation of a new ministry of community care, along with increased investment, but the British Government chose not to implement these recommendations.²⁸⁷

A welfare market is thought to provide more choice and independence for people that are dependent upon public financial support.²⁸⁸ At the same time, welfare markets allow private

²⁸³ Means, Richards, and Smith, *Community Care*. P. 52.

²⁸⁴ Means, Richards, and Smith. P. 54.

²⁸⁵ Means, Richards, and Smith. P. 54.

²⁸⁶ Means, Richards, and Smith. P. 55.

²⁸⁷ Means, Richards, and Smith. P. 55.

²⁸⁸ Bode, *The Culture of Welfare Markets: The International Recasting of Pension and Care Systems*. P. 19.

organisations to have an influence on the type and quality of care that is provided.²⁸⁹ Regardless if this voice of private companies is beneficial, or not, it is the result of transferring authority away from governments, and instead, giving the authority to private interests. This is not the goal that the advocates for de-institutionalisation have in mind when they work to wrest control of people who have intellectual disabilities away from the state. Instead, the social movement for de-institutionalisation promotes that authority must reside with people who have disabilities and their advocates. Despite this concern, it is well documented that community care, no matter what the costs, has superior outcomes compared to institutionalised care.²⁹⁰ Of note, the Government of Saskatchewan has mitigated the worry that private care providers will unduly influence standards of care by taking direction about standards of care from organisations such as Inclusion Saskatchewan.

In Britain, Griffiths' recommendations fit the new economic paradigm pursued by the British Government as they called for privatising welfare provision for people who have disabilities, and de-centralising the responsibility of care away from the State, transferring it to regional authorities or individuals. These reforms, however, suffered criticism concerning the quality of care provision and intra-agency problems.²⁹¹ Not only was there not enough care packages for all people that needed them, but the quangos were soon immersed in internal debates about which clients were the most eligible for care packages, and ultimately, eligibility for services became increasingly narrow.²⁹² Access to care was described by clients as a "postcode lottery" indicating that regional authorities had a finite number of care packages to

²⁸⁹ Bode. P. 21.

²⁹⁰ Stancliffe et al., "The Economics of Deinstitutionalization." P. 11.

²⁹¹ Means, Richards, and Smith, *Community Care*. P. 84.

²⁹² Means, Richards, and Smith. P. 65.

give, regardless of the actual numbers of people requiring care.²⁹³ These developments were disappointing to advocates for de-institutionalisation.

The transfer of care provision to private interests was successful. By 2005, the private sector provided 73% of home care, compared to only 2% in 1992.²⁹⁴ Yet, the welfare market was struggling as business was sporadic, profit margins were slim, high staff turnover negatively affected care quality, and entrances and exits to the market were frequent.²⁹⁵ Also, there were methods of cost reduction that increased pressure upon service providers, such as capping the prices paid to care homes, which rendered some care homes unable to make a profit, or even forced them to operate at a loss.²⁹⁶ This led to many care providers resorting to business models based on economies of scale.²⁹⁷ Large corporations, often publicly traded in international financial markets, began to provide care in large facilities.²⁹⁸ These developments were not in line with the values of the social movement for de-institutionalisation, and it appears that state operated institutional facilities have been replaced by institutional facilities that are operated by private corporations.

Despite the attempt to increase efficiency, Britain discovered that community care is more expensive than state operated institutional care was. Some assert that community care in Britain is more expensive than other nations because British care workers are paid the same rate whether they are paid by the public or the private sector.²⁹⁹ As well, some assert that the government lost the benefit of unpaid labour performed by institutionalised people who were

²⁹³ Means, Richards, and Smith. P. 65.

²⁹⁴ Means, Richards, and Smith. P. 71.

²⁹⁵ Means, Richards, and Smith. P. 71.

²⁹⁶ Means, Richards, and Smith. P. 73.

²⁹⁷ Means, Richards, and Smith. P. 74.

²⁹⁸ Means, Richards, and Smith. P. 74.

²⁹⁹ Eric Emerson et al., "Costs and Outcomes of Community Residential Supports in England," in *Costs and Outcomes for Community Services for People with Intellectual Disabilities*, ed. Roger Stancliffe and Charlie Lakin (Baltimore: Paul H Brooks Publishing, 2005). P. 159.

expected to dress, feed, and supervise fellow residents.³⁰⁰ It is also believed that many institutionalised people were denied release because they were considered too valuable as a source of labour.³⁰¹ These benefits of unpaid labour by institutionalised residents were an international phenomenon. In the United States, for example, the costs of staffing an institutional facility were controlled through underfunding programs, understaffing, and the use of indentured labour.³⁰² Despite these cost saving measures, building maintenance costs remained high.³⁰³ When institutionalised populations began to decline, labour and maintenance costs rose significantly due to dis-economy of scale.

Although the policy of community care in Britain is more expensive than their former policy of institutionalisation, in the United States, community care is far less costly than institutionalisation. This is because, in the United States, the private sector care workers are paid substantially less than public sector care workers, meaning that substantial savings were attained through the privatisation of care. For example, in 2000, hourly wages for American public sector care workers was \$11.57, while private sector workers earned \$8.72.³⁰⁴ Wages are thought to be the largest cost in providing residential care, comprising between 77 and 87 percent of total expenditures.³⁰⁵ These costs might be alleviated based on how many staff are on duty at a time, adjusting rates of pay, limiting benefits, employing para-professionals rather than professionals, and by outsourcing certain services.³⁰⁶ Public sector employers are constrained by state

³⁰⁰ Johnson and Traustadottir, "Deinstitutionalization People with Intellect. Disabil. Out Institutions."

³⁰¹ Johnson and Traustadottir.

³⁰² Braddock et al., "Public Spending for Developmental Disabilities in the United States: An Historical-Comparative Perspective." P. 29.

³⁰³ Braddock et al.

³⁰⁴ Stancliffe et al., "The Economics of Deinstitutionalization." P. 11.

³⁰⁵ Stancliffe et al. P. 11.

³⁰⁶ Stancliffe et al. P. 12.

regulations and labour contracts, but non-union, private employers were not bound by these restrictions.

When American States chose to privatise provision of care by introducing welfare markets, they enjoyed much greater savings from their reforms. Not only were they able to save on labour costs, as private sector employees tended to receive lower rates of pay, but they also gained efficiency through eliminating the increasing dis-economy of scale occurring in state-run institutional facilities.³⁰⁷ Britain's savings were offset by the higher cost of labour in community care, but in the United States, community care turned out to be an average of 14.6 percent lower per person than institutionalised care.³⁰⁸ Additionally, savings varied from state to state as due to the differences in regulations, and savings were dependent upon differing standards for staffing ratios, required hours of program participation, staff qualifications, and training costs.³⁰⁹

De-construction of Care through Neglect and Policy Drift:

Neglect and Policy Drift continue to characterise the architecture of care for people who have disabilities. In order to mitigate the effects of de-institutionalisation, there should be adequate investment in community infrastructure. Otherwise, institutional facilities will close and the formerly institutionalised people will have few places where they may reside and receive care. The United States National Association of Superintendents of Public Residential Facilities for the Mentally Retarded determined in 1974 that de-institutionalisation included three processes. These were prevention of new admissions through the development of community care, preparing institutionalised residents for a return to the community through training and rehabilitation programs, and establishing, and maintaining, residential environments in the

³⁰⁷ Stancliffe et al. P. 14-15.

³⁰⁸ Stancliffe et al. P. 11.

³⁰⁹ Stancliffe et al. P. 15.

community that would protect human and civil rights.³¹⁰ Therefore, de-institutionalisation is not as simple as merely closing institutional facilities. It requires forethought, planning, and investment.

While many governments have been very willing to close institutional facilities, they have been less focused on investing in alternative forms of care infrastructure. Community care, which is the form of care advocated by the social movement for de-institutionalisation, has sometimes been justified by governments as the less expensive mode of care. However, the community care offered by some governments has turned out to be merely a less expensive form of institutionalisation in a smaller setting.³¹¹ For example, Maria, an Australian woman with moderate intellectual disability was released from a large institutional facility to live in a community residence. Some of the other residents living in the same home as Maria would wander away when unsupervised, and therefore, Maria's new home was a locked facility.³¹² Although Maria did not have a problem of wandering away, her freedom was limited in order to accommodate other people.³¹³ Instead of placing Maria in an appropriate living situation that suited her care needs, living in a locked facility meant that she remained segregated from the community, unable to come and go as she pleased.³¹⁴ Thus, Maria remains institutionalised, unable to make her own decisions. By not taking steps to remedy Maria's situation, care authorities are neglecting the ideals of the social movement for de-institutionalisation.

³¹⁰ Thurlow et al., "Deinstitutionalization and Residential Services: A Literature Survey." P. 3.

³¹¹ Means, Richards, and Smith, *Community Care*. P. 5.

³¹² Julian Gardner and Louise Glanville, "New Forms of Institutionalization in the Community," in *Deinstitutionalization and People with Intellectual Disabilities: In and out of Institutions*, ed. Kelley Johnson and Rannveig Traustadottir (London: Jessica Kingsley Press, 2006). P. 227.

³¹³ Gardner and Glanville. P. 227.

³¹⁴ Gardner and Glanville. P.228.

When constructing an architecture of care, governments are faced with the pressures of financial restrictions and legislation, as well as the pressures from public consultation and user advocacy groups.³¹⁵ Additionally, there is input to consider from research based evidence concerning the composition of the labour market, and the tendency toward sub-standard service by underpaid staff, which in turn is believed to be a contributing factor in the abuse of care receivers.³¹⁶ In Australia, large institutional facilities were described as overcrowded, underfunded and understaffed, and where segregated persons with intellectual disabilities were isolated from: "[c]ontact with the general community, and provided with a deficient living environment".³¹⁷ Some advocates for de-institutionalisation assert that institutionalised care has only rarely been replaced with high quality community-based services due to the culture of neglect that permeates the infrastructure of care.³¹⁸ The example of Maria, relocated to the 'community', but remaining in a locked facility is a testament to the failure of some governments to provide appropriate infrastructure.

The culture of neglect within institutions was elaborate and characterised by abuse. This neglect was both real and symbolic. For instance, even in settings where actual abuse did not occur, institutionalised people were de-humanised through the neglect of their ability to have preferences or make choices. Even the most mundane options were dictated, such as how much milk and sugar could be added to tea, and the use of communal underwear.³¹⁹ Institutionalised people were described by their advocates as being symbolically de-humanised as: "[b]y the very fact (of their institutionalisation) society is defining them as socially dead because society has

³¹⁵ Means, Richards, and Smith, *Community Care*. P. 21.

³¹⁶ Means, Richards, and Smith. P. 21.

³¹⁷ Gardner and Glanville, "New Forms of Institutionalization in the Community." P. 224.

³¹⁸ Means, Richards, and Smith, *Community Care*. P. 21.

³¹⁹ Means, Richards, and Smith. P. 39.

effectively washed their hands of the inmates as significant human beings”.³²⁰ Unless transition into the community involves the ability to make choices about living arrangements and participation in community life, an institutionalised person has not been de-institutionalised. They have merely become trans-institutionalised.

There is evidence that, from the point of view of governments, that the main motivation for de-institutionalisation was to mitigate the high costs associated with providing care in institutional settings.³²¹ Many believe that when governments were faced with rising costs from institutional facilities, that they began to transfer resources toward community-care because it was perceived as less expensive, and since most people who have disabilities have always lived in the community, and that further costs would be saved by relying on families to provide care.³²² Many governments also took the stance that too generous funding would undermine the role of the family in caring for their loved ones.³²³ Not everyone agreed with this ethic and asserted that families' experience too much strain without financial help and respite services, leading them to give up their care giving roles altogether. It was argued that families unable to withstand the strain of caregiving, would transfer responsibility for care back to the state and this would result in even higher expenditures.³²⁴ There was also the argument that people who have disability have the right not to be made dependent upon family members for the provision of care.³²⁵ Despite this disagreement amongst policy makers, few new policies are emerging that enable care receivers and their advocates to determine who should perform care giving

³²⁰ Means, Richards, and Smith. P. 31.

³²¹ Means, Richards, and Smith. P. 41.

³²² Means, Richards, and Smith. P. 44-46.

³²³ Means, Richards, and Smith. P. 46.

³²⁴ Means, Richards, and Smith. P. 47.

³²⁵ Means, Richards, and Smith. P. 47.

activities.³²⁶ The difficulty in resolving these debates has led some governments to experience policy drift, which ultimately neglects construction of adequate care architecture.

Despite criticisms of how governments have underfunded community care, governments have not rid themselves of welfare spending. In the United States, \$373 billion was spent on the care of persons with disabilities for the 2001 fiscal year.³²⁷ Of this investment, 64 percent was provided by the federal government, 31 percent from the states, and 5 percent from local school districts that provide special education services.³²⁸ Out of this \$373 billion, \$107.6 billion was allocated for income maintenance, and general healthcare took a share of \$74.6 billion.³²⁹ As well, every state, except Mississippi were allocating the majority of funding for persons with intellectual disabilities to community care during the 2002 fiscal year.³³⁰ Furthermore, spending was incrementally increased by 10 percent per year between 1977 and 2002.³³¹ In keeping with the values of de-institutionalisation, 298,270 persons who have intellectual disabilities were served in community settings of one to six people.³³² Small residence size has been recognised as a determinant of positive outcomes.³³³ Despite some gaps in service and quality, these figures show that care and funding for who have disabilities are not being abandoned.

The ability of governments to increase investment in community care has been limited. American states, for example, face large deficits, and are legally required to balance their

³²⁶ Means, Richards, and Smith. P. 47.

³²⁷ Braddock et al., "Public Spending for Developmental Disabilities in the United States: An Historical-Comparative Perspective." P. 30.

³²⁸ Braddock et al. P. 31.

³²⁹ Braddock et al. P. 31.

³³⁰ Braddock et al. P. 31.

³³¹ Braddock et al. P. 33.

³³² Braddock et al. P. 33.

³³³ David Felce and Eric Emerson, "Community Living: Costs, Outcomes, and Economics," in *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, ed. Roger Stancliffe and Charlie Lakin (Baltimore: Paul H. Brooks Publishing, 2005). P. 45.

budgets³³⁴ This has forced some governments to reduce spending or increase taxation in order to fund programs, and this inability to provide funding is coupled with increasing pressure from the aging of both caregivers and care receivers.³³⁵ As well, underfunding has been revealed by a number of lawsuits filed by people that are entitled to benefits, but are not receiving them.³³⁶

Although no association has been found between outcomes and level of investment, it has been recommended that outcomes will improve if per person funding is increased, especially if this funding is applied to increasing the numbers of staff to care receiver.³³⁷ It has also been suggested that inefficient delivery of care has been caused by failing to allocate resources by need, and that some care receivers have been allocated more benefits than needed.³³⁸

Fewer than 20 percent of people who have intellectual disability live apart from their families, which means that families are the largest providers of care.³³⁹ Despite this fact, most resources are directed at those care receivers living in residential settings away from their families, and families receive the lowest form of public assistance to care for their loved ones.³⁴⁰ Contributing to the culture of neglect, there are few policy initiatives, and little research, that is directed toward improving resources for family care.³⁴¹ Just the same, many governments have been reducing resources available to family caregivers. In the United States, less than 8 percent of resources were directed toward family care during the 1990s, and then welfare reform

³³⁴ Braddock et al., "Public Spending for Developmental Disabilities in the United States: An Historical-Comparative Perspective." P. 39.

³³⁵ Braddock et al. P. 39.

³³⁶ Braddock et al. P. 41.

³³⁷ Felce and Emerson, "Community Living: Costs, Outcomes, and Economics." P. 46.

³³⁸ Felce and Emerson. P. 58.

³³⁹ Darrell Lewis and David Johnson, "Costs of Family Care for Individuals with Developmental Disabilities," in *Costs and Outcomes for of Community Services for People with Intellectual Disabilities*, ed. Roger Stancliffe and Charlie Lakin (Baltimore: Paul H. Brooks Publishing, 2005). P. 63.

³⁴⁰ Lewis and Johnson. P. 63.

³⁴¹ Lewis and Johnson. P. 63.

legislation in 1996 discontinued income subsidies to families caring for 100,000 children who have intellectual disability.³⁴²

Unfortunately, little attention has been paid to the funding requirements of families as most studies focus on costs to the state.³⁴³ It is known, however, that family caregivers incur financial, psychological, and opportunity costs when caring for relatives who have an intellectual disability.³⁴⁴ Costs were found to be between 8 and 20 percent higher than typical families, and no income point has been identified where a child who has intellectual disability has their needs met within the family's normal budget.³⁴⁵ Additionally, having a family member who has a disability has been found to be associated with lower family income, due to the opportunity cost of the principal caregiver having to forgo paid employment.³⁴⁶ Complicating matters further, it is very difficult for family caregivers to navigate the welfare markets. It has been found that acting as care managers will often overwhelm families.³⁴⁷ Creating even more hardships for (British) families with children who have disabilities is that the poorest families of all, those receiving welfare payments, must return to work when specified to, or lose their benefits altogether.³⁴⁸

The architecture of care appears to favour surrendering children to the state authorities in order to reduce the financial burden on the family. For example, in Canada, the foster parents caring for children with intellectual disabilities will receive hundreds of thousands of dollars in funding and pay to deliver care, but families caring for their own children receive extremely little

³⁴² Lewis and Johnson. P. 63.

³⁴³ Lewis and Johnson. P. 67.

³⁴⁴ Lewis and Johnson. P. 67-68.

³⁴⁵ Lewis and Johnson. P. 70.

³⁴⁶ Lewis and Johnson. P. 71.

³⁴⁷ The Stakeholders, "Interview Data."

³⁴⁸ Lewis and Johnson, "Costs of Family Care for Individuals with Developmental Disabilities."

for their efforts.³⁴⁹ As another example, American policies have narrowed subsidy eligibility requirements, which excluded thousands of families from eligibility.³⁵⁰ Additionally, benefits cease at age 18 unless the care receiver is deemed medically unable to work, and in 1998, this policy resulted in the loss of 56 percent of people who have disabilities who turned 18 in that year.³⁵¹ There are few rewards for gaining employment as any financial support for family caregivers ceases once their child receives income from employment.³⁵²

Conclusion:

Both the social movement for de-institutionalisation and governments in pursuit of monetarist policies have achieved some common goals. The most important of these common goals is that governments and advocates for de-institutionalisation agree that institutional facilities must be closed, and that people who have intellectual disabilities should receive care within the community, and this project has been underway for decades. Despite the many institutionalised people who have been transitioned to community care, debate continues over what true de-institutionalisation is, what community-care should entail, and how much governments should invest in social programs that support people who have intellectual disabilities and their families.

Although the method of de-institutionalisation by creation of welfare markets has been a construct of economic doctrines that demand a drawing down of the Welfare State, de-institutionalisation does not necessarily depend upon de-constructing the Welfare State. Community-care can, and has, operated within a Welfare State apparatus, and thus is not an invention of the free-market. Many people believe that community-care and family care is

³⁴⁹ The Stakeholders, "Interview Data."

³⁵⁰ Lewis and Johnson, "Costs of Family Care for Individuals with Developmental Disabilities." P. 83.

³⁵¹ Lewis and Johnson. P. 83.

³⁵² Lewis and Johnson. P. 83.

underfunded by governments, and that policies are thwarting the ability of families to care for their children who have intellectual disabilities. Therefore, if a government chooses to promote family care provision over other forms of care, it would be prudent to invest in programs that will effectively support the efforts of families to care for their loved ones who have disabilities. When families struggle to continue caring for vulnerable relatives, especially as the care givers and the care receivers age, governments may find themselves in a position of paying a premium for developing care infrastructure.

Chapter 4

100 Years of Saskatchewan Policies that Concern Care for People who have Intellectual Disabilities

Due to social pressure and a desire for economic reforms, many governments have chosen to reverse their policies of institutionalisation. In a process of de-institutionalisation, governments are closing institutional facilities and instead facilitating care options that are located within the community. The main intent of de-institutionalisation is to allow formerly institutionalised people to integrate as full members of the community. This is the ideal narrative, but not always the reality. Instead, the road to de-institutionalisation is often littered with conflict, failed policies, and under-investment.

To be functional, policies of de-institutionalisation must be accompanied by a policy of inclusion. It is a human right for people who have intellectual disability to live alongside other members of society, rather than to be segregated from society. This right to inclusion was first recognised by the United Nations General Assembly resolution 2856 of 20 December 1971, which declared that people who have intellectual disabilities have the same rights as other human beings, including the right to proper medical care, physical therapy, education, economic security, and to live in the community, and to participate in community life. The segregation of people who have intellectual disabilities from society has historically been one of the goals of institutionalisation, but now few would agree that segregation is an ideal situation. Instead of segregation, inclusion advocates and the medical community favour inclusion.

In 2019, when Saskatchewan chose to permanently close a large institutional facility that was used to provide care for people who have intellectual disability, inclusion advocates believed that the ideal narrative of de-institutionalisation had been achieved. While costs and economic ideologies were at issue, there was equal emphasis placed on the reality that institutional care is

no longer considered the best practice in care for people who have intellectual disabilities. The Government of Saskatchewan determined to close Valley View Centre because the buildings were dilapidated and the cost to repair them was not economically justifiable, but more importantly, the Government of Saskatchewan had committed to improving the life quality of people who have intellectual disabilities. A commitment to improving the material and social conditions for people who have intellectual disability necessitates conformity with the current best recognised practices for care, which demand a policy of inclusion.

In 2011, Premier Brad Wall campaigned for re-election on the promise that his Saskatchewan Party would expand incomes and services for people that have intellectual disabilities.³⁵³ To achieve this goal, Premier Wall promised to increase benefits to individuals over a four-year period, raising each person's monthly allowance to include an additional \$100 to \$350 dollars per month, as well as an additional \$33.3 million dollars of investment in increased benefits and services.³⁵⁴ Speaking passionately about his intention to improve lives, Premier Wall stated: "[w]e'll continue about the business of making sure that there is the dignity of a home for people with intellectual disabilities, that there is a respite program where needed and that there is day programming needed as well. I can't imagine a more important function for government than this".³⁵⁵ Premier Wall won re-election and to the increased satisfaction of inclusion advocates, the Government of Saskatchewan began to deeply invest in the creation of community living infrastructure.

³⁵³ Jennifer Graham, "Saskatchewan Election: Brad Wall Promises Expansion OF Program For Disabled, Criticizes Costly NDP Promises," *The Canadian Press*, October 17, 2011, https://www.huffingtonpost.ca/2011/10/17/sask-party-aims-for-affo_n_1016722.html.

³⁵⁴ Jennifer Graham.

³⁵⁵ Jennifer Graham.

By 2013, that investment became a \$62.5 million-dollar project that created 500 positions in community-based care organisations, as well as the opening of 75 new group homes.³⁵⁶ Additionally, it was announced that, since 2008, the ministry had “[c]leared the waitlist of intellectually disabled people requiring homes and programs that meet their special needs”.³⁵⁷ These improvements in care and services for people who have intellectual disability, along with the closure of the Valley View Centre, have pleased inclusion advocates.

When Premier Wall declared: “[i]t is our government’s goal to make Saskatchewan the best place to live for people with disabilities”,³⁵⁸ inclusion advocates took the opportunity to assist the Government of Saskatchewan in making appropriate choices that would lead to goal realisation. This was not the first time, however, that the Government of Saskatchewan had paid attention to service provision for citizens who have intellectual disability. In fact, Brad Wall’s focus on people who have intellectual disability has long enjoyed a place on Saskatchewan’s public policy agenda.

Getting on the Agenda: Saskatchewan’s long history of focus on people who have intellectual disability:

For an issue to transform from an idea to government policy, it must make quite a long journey. The idea must first get on the government’s agenda. Then, this idea must be viable and realistic enough that will find its way onto the decision agenda. At the same time, there must be a window of opportunity so that actors may put their ideas into action. All these steps occurred along the journey of Saskatchewan’s disability policy innovation.

³⁵⁶ Murray Mandryk, “Wall’s Understanding Helps Disabled,” *The Leader Post*, April 23, 2013, <http://gos.densan.ca/sk/showfile.asp?Lang=E&URL=/archivesk/130423/relp/1304230N.htm>.

³⁵⁷ CBC News, “Service Waitlist for Intellectually Disabled Cleared,” *CBC.ca*, April 22, 2013, <https://www.cbc.ca/news/canada/saskatchewan/service-waitlist-for-intellectually-disabled-cleared-1.1335311>.

³⁵⁸ CBC News.

There are very important reasons why the needs of people who have intellectual disabilities keep finding a place on Saskatchewan's government agenda. While few issues can command such an attention over a 100-year period, even fewer issues manage to be acted upon. In terms of advocacy for people who have intellectual disabilities, one might say that the stars were frequently aligned in Saskatchewan, which ultimately allowed many opportunities for policy change. These stars in question were the policy entrepreneurs, ideologies concerning economic organisation and social justice, and the periodically opening policy window.

First, there was the attention to care delivery reform through the vision of Tommy Douglas and the CCF. Then, there was the work of Saskatchewan scholars such as Lorne Elkin whom, in addition to his role as supervisor of psychological research at the STS, was a well published and vocal proponent for de-institutionalisation. Elkin has been described as a man who was "[a] champion of people who are discriminated against on the basis of intellectual abilities".³⁵⁹ Elkin's work consistently informed the government that best practices for care were changing, and that the status quo of institutionalised care were increasingly inappropriate.

The next great impetus for attention came in the person of Premier Brad Wall. Just as former Premier Tommy Douglas was personally inspired to innovate health care in Saskatchewan, so too was Premier Brad Wall motivated to improve conditions. Premier Wall has a close family member with an intellectual disability, and this personal family experience in navigating the care resources available in Saskatchewan influenced Premier Wall's agenda. Frank Baumgartner and Bryan Jones assert that officials place issues on the agenda to protect the interests of their constituents, to satisfy their own interests, or to accomplish something that they

³⁵⁹ Don Mitchell, "Lives Lived: Lorne Elkin, 77," *The Goble and Mail*, July , <http://www.theglobeandmail.com/life/facts-and-arguments/lives-lived-lorne-elkin-77/article25529276/>.

personally believe to be in the interest of the public good.³⁶⁰ In this case, Premier Wall appears to have been motivated by all three types of interests.

Due to the lack of resources in Saskatchewan at the time, Premier Wall's family member had to be provided care within another province.³⁶¹ Many would agree that such a situation is unacceptable and that improvements in Saskatchewan's healthcare services therefore deserve a prominent place on the policy agenda. However, it is also reasonable to suggest that Premier Wall himself was the catalyst for the high attention to this specific issue, at this exact moment in time. Likewise, Premier Douglas was the catalyst for innovation in care just at the moment when it became clear that the North Battleford Insane Asylum and the Weyburn Mental Hospital were inadequate for the province's needs, and then Lorne Elkin became the catalyst for change in the government's attitudes concerning institutional versus community living. The participation of actors such as Douglas, Elkin, and Wall, helped to ensure that the needs of people who have intellectual disabilities remained on the Government of Saskatchewan's policy agenda. There are, after all, a surplus of important issues that require attention.

The attention aroused by Douglas, Elkin, and Wall, are rooted in ideas of social justice. Still, it is important to understand that ideas about how to achieve social justice have evolved over the last century and that ideas concerning social justice for people who have disabilities were very different in 1930 than they were in 2012. In Tommy Douglas's time, ideas about how to care for people who have disability were highly informed by eugenics. By the time Elkin

³⁶⁰ Bryan Jones and Frank Baumgartner, *The Politics of Attention: How Government Prioritizes Problems* (Chicago: University of Chicago Press, 2005).

³⁶¹³⁶¹ This information is gleaned from personal communication with members of the Steering committee. As far as I can find, there is no published source for this material.

became Supervisor of Psychological research at the STS, eugenics had become discredited theory, and eugenics policies were in the process of being abandoned.

Alongside the desire for social justice for people that have intellectual disability is the economic aspect of delivering care. In the time of Tommy Douglas, institutionalised care was complimentary to the dominant social and economic ideologies of the day, which eventually favoured the expansion of a Welfare State. Thus, the history of the social and economic motivations behind the development of the Saskatchewan Training School are useful in revealing how social ideas and economic aspirations are intertwined. For example, the location of the Saskatchewan Training School in Moose Jaw was a deliberate political and economic decision.

In 1938, the City of Moose Jaw began to aggressively campaign for an institution to be built for the purpose of stimulating local growth.³⁶² There was stiff competition from both the cities of Regina and Saskatoon, but in the end, the Government of Saskatchewan was convinced to locate the new institution in Moose Jaw. The reason for this decision was mainly due to the insistence that the region was able to produce cheaper coal, had warmer temperatures, a high population of eager employment seekers, and a perceived lack of investment by the province.³⁶³ Part of the argument for the location of the new institutional facility near the City of Moose Jaw was that the city felt their region had been “[n]eglected, if not discriminated against, in the matter of public institutions”.³⁶⁴ Moose Jaw got the institutional facility they long desired, but only after Moose Jaw Mayor Jack Corman was elected to the Saskatchewan Legislature in 1944 and became Attorney General.³⁶⁵ By 1950, the Moose Jaw Times Herald promoted the decision

³⁶² Dan Sydiaha et al., *A Question of Rights: Saskatchewan's Mentally Retarded People Move From Institutions to the Community*. (Moose Jaw: Sociology and Politics of Change in Programs for the Mentally Retarded -- National Health Grant 608-1000-30, 1976). P. 12

³⁶³ Sydiaha et al. p. 12

³⁶⁴ Sydiaha et al. p. 12

³⁶⁵ Sydiaha et al. p. 14

enthusiastically stating that: “[i]t is not at all surprising that local businessmen are looking at the locating of the institution here from the dollar and sense viewpoint. It will not be an institution of which the public will generally make much use, but its presence in the community will be felt in many ways”.³⁶⁶ Attorney General Corman’s sod-turning speech agreed with this assessment, indicating that there were plans for the institution to double or triple in size and that it would be of great value to Moose Jaw due to the employment that it would provide.³⁶⁷

Some scholarship explicitly asserts that policy change that is advertised as being an improvement in the delivery of care for persons who have intellectual disability: “[i]nvariably have political and socio-economic consequences, which are the primary motive for the changes. In other words, the community, the politicians, and those providing the service, profit more from the change than those for whom the change is ostensibly planned”.³⁶⁸ Due to the entanglement of social ideas with economic prescription, it is fair to say that economics and self-interests are strong motivators for social policy change.

In the case of Saskatchewan, the ensemble of policy actors had the benefit of being in the right place at the right time, enabling the agenda to be focused upon the needs of persons who have intellectual disabilities. Actors such as Attorney General Corman, Premier Douglas, and Premier Wall, inspired attention toward people who have intellectual disabilities for both social and economic reasons. During different economic periods, the policies of institutionalisation and de-institutionalisation have each been advertised as being fiscally responsible and the best form of care available. Thus, it is necessary to understand that policies of institutionalisation and de-institutionalisation each correspond to a complex combination of economic and altruistic values.

³⁶⁶ Sydiaha et al. p. 14

³⁶⁷ Sydiaha et al. p.14

³⁶⁸ Sydiaha et al. P.2

The high attention the Government of Saskatchewan has paid to the needs of people who have disability would usually fall into the category of ‘disproportionate attention’. That is not to say that the attention is unwarranted, but rather, that this issue is getting more attention than what is normally expected in a landscape filled with issues. As opined by one Saskatchewan newspaper columnist, there are many other issues that are not receiving the government’s attention.³⁶⁹ Yet, the same columnist admits that while he is criticising Wall for disproportionate attention, he is also applauding Wall for accomplishing so much for people who have intellectual disabilities, as a lack of attention to the issue would have had little impact at the polls.³⁷⁰ Such high attention to tightly focused policy issues, by multiple actors, and that have little impact in the polls, indicate that there is more at play than purely economic or self-interested motivations.

We can assume that disproportionate attention to a policy issue can be related to ideological principles, and that adherence to these principles can push other policy issues aside, even larger policy issues. In the case of the closure of the Valley View Centre, however, there is the added element that since joining the Dominion of Canada in 1905, Saskatchewan’s economic policy has greatly relied on a policy of institutionalisation. The policy of institutionalisation became so entrenched within Saskatchewan’s economy that more than 100 years later, the Government of Saskatchewan is still working to free itself from the effects. Not only has Saskatchewan lagged behind many other jurisdictions in closing institutional facilities, but the primacy of place that had historically been given to institutionalisation has made it difficult to de-institutionalise. The policy direction of recent decades has been on a course of de-institutionalising people, but also de-institutionalising many of the economic policies that have supported Saskatchewan’s welfare state. Therefore, the attention to disability policy in

³⁶⁹ Mandryk, “Wall’s Understanding Helps Disabled.”

³⁷⁰ Mandryk.

Saskatchewan only appears disproportional if care is not taken to view the situation as a project of perceived economic reform.

The Policy Window Opened: Three instances of opportunity for improving the delivery of care for Saskatchewan residents who have intellectual disability:

In reference to Saskatchewan policies for persons with intellectual disabilities, Douglas, Corman, Wall, and Elkin, were ‘policy entrepreneurs’. John Kingdon describes a policy entrepreneur as someone who:

could be in or out of government, in elected or appointed positions, in interest groups or research organisations. But their defining characteristic, much as in the case of a business entrepreneur, is their willingness to invest their resources—time, energy, reputation, and sometimes money—in the hope of a future return. That return might come in the form of policies of which they approve, satisfaction from participation, or even personal aggrandisement in the form of job security or career promotion.³⁷¹

As policy actors, Douglas, Corman, Wall, and Elkin, each came to the table with their own vision for what direction they believed that Saskatchewan policy should take, and they certainly invested their time, energy and reputations into realising their goals. While some policy entrepreneurs may be purely self-interested, this is unlikely the case for this ensemble of actors. In this instance, each individual actor was clearly motivated by their personal vision of the public good, whether it be for economic prosperity, improved care for persons with disabilities, or a combination of these goals. Still, a strong ensemble of policy entrepreneurs is not enough to affect policy change. They must have opportunity.

There were three moments over the last century when a window opened for improving Saskatchewan policy concerning the care of people who have intellectual disability. These

³⁷¹ John Kingdon, *Agendas, Alternatives, and Public Policies*, 2nd ed. (New York City: Longman, 1995). P 122-123.

moments were the era of institutionalisation, an era of transition, and an era of de-institutionalisation. Through the contemporary lens, the policies have been less than optimal, but they have incrementally improved over time.

The first moment, which can be characterised as the era of institutionalisation, began in 1905 when Saskatchewan joined the Dominion of Canada. The Federal Government believed that something should be done about the “dangerous lunatics” that were present in the North-West Territories, which at that time included Saskatchewan.³⁷² Coupled with the notion that institutional facilities were good for the economy, popular sentiment called for large facilities to be built in order to accommodate persons who were considered a danger to both society and to themselves. It was also believed that adopting the example of British institutions and economic policy would have a civilising effect on the region.³⁷³

Quite rapidly, the new Province of Saskatchewan built two large institutional facilities for the care of people that were then described as “Mental Defectives”. The umbrella term of “Mental Defectives”, referred to people who have intellectual disability, a mental illness, or who were somehow failing to live up to societal expectations. The North Battleford Insane Asylum, which opened in 1913,³⁷⁴ and the Weyburn Mental Hospital, which opened in 1921,³⁷⁵ were soon overcrowded. The overcrowding of existing facilities and advances in medical knowledge led to a desire to open an institutional facility dedicated solely for the care of people with intellectual disabilities. This goal was achieved with the opening of the Saskatchewan Training School in

³⁷² Soo Line Historical Museum, “Weyburn Mental Hospital,” Virtual Museum.ca, 2004, http://www.virtualmuseum.ca/sgc-cms/histoires_de_chez_nous-community_stories/pm_v2.php?id=exhibit_home&fl=0&lg=English&ex=00000363&pg=0.

³⁷³ Erika Dyck and Alex Deighton, *Managing Madness: Weyburn Mental Hospital and the Transformation of Psychiatric Care in Canada* (Winnipeg: University of Manitoba Press, 2017).

³⁷⁴ Saskatchewan Health Authority, “Saskatchewan Hospital - Reflecting on a Century of Care,” [saskhealthauthority.ca](https://www.saskhealthauthority.ca/news/stories/Pages/2018/Aug/Saskatchewan-Hospital.aspx), 2018, <https://www.saskhealthauthority.ca/news/stories/Pages/2018/Aug/Saskatchewan-Hospital.aspx>.

³⁷⁵ Soo Line Historical Museum, “Weyburn Mental Hospital.”

1955, a full 15 years after the Hincks Royal Commission determined that people who have intellectual disability should not be institutionalised in the same facilities as people who have mental illness.³⁷⁶

Out of necessity, the Government of Saskatchewan had been investing in community care even before the STS opened. Despite the continual expansion of existing mental hospitals and the construction of new institutional facilities, they were always operating significantly above capacity. During the Great Depression of the 1930s, psychiatric wings were added to many General Hospitals, and the Government of Saskatchewan viewed these new facilities as an example of care in the community.³⁷⁷ This measure, however, was partly in response to the extreme overcrowding in the segregated mental hospitals, that was in turn due to the increasing numbers of the population that had become eligible for institutionalisation.

The sheer numbers of people experiencing committal was enough of a concern that the Mental Defectives Act of 1930 was repealed and replaced by the Mental Hygiene Act of 1936, which provided a safeguard against wrongful committal and made it easier for institutionalised people to attain release back to the community.³⁷⁸ Reforming the process of institutionalisation did not solve the crisis of overcrowding, however, as the institutional facilities were operating at 189% over capacity during the 1940s.³⁷⁹ By 1947, outpatient mental health clinics were established within several cities allowing people to receive care without becoming segregated

³⁷⁶ Sydiaha et al., *A Question of Rights: Saskatchewan's Mentally Retarded People Move From Institutions to the Community*. P.5.

³⁷⁷ Dyck and Deighton, *Managing Madness: Weyburn Mental Hospital and the Transformation of Psychiatric Care in Canada*.

³⁷⁸ Ministry of Social Services, "Appendix D: History of Mental Health and Addictions Services in Saskatchewan" (Regina, n.d.), file:///C:/Users/britt/Downloads/99240-Mental_Health_and_Addictions_Action_Plan_Appendices (1).pdf. P. 18

³⁷⁹ Ministry of Social Services. P. 18.

from the community.³⁸⁰ This was after two commissioned studies called for mental health treatment to be delivered within the community.³⁸¹

During the 1950s and 1960s, pressures against policies of institutionalisation were intensifying. For example, the Canadian Mental Health Association opened a division in Saskatchewan in 1949.³⁸² This organisation had a tremendous impact on attitudes toward mental illness and called for governments to replace institutional facilities with care in the community.³⁸³ Other small changes were occurring that served to create options beyond institutionalisation, such as the public funding of some special education programs within the community.³⁸⁴ Very importantly, Saskatchewan's medical experts were advising the Government of Saskatchewan that people should only be institutionalised if their case was extreme, and that most people who have intellectual disability should be cared for within the community.³⁸⁵ As well, the development and use of anti-psychotic medications profoundly improved the health of many people, and fewer people required institutionalisation. This caused the population of institutional facilities for the treatment of mental illnesses to decline.

A major development was the 1955 'Saskatchewan Plan' that called for closure of both the Saskatchewan Hospital in North Battleford, and the Weyburn Mental Hospital.³⁸⁶ Designed as a tool of de-institutionalisation, the Saskatchewan Plan proposed the development of community-based in-patient and out-patient mental health centres within eight separate health

³⁸⁰ Ministry of Social Services. P. 18.

³⁸¹ Ministry of Social Services. P. 18.

³⁸² Ministry of Social Services.

³⁸³ CMHA, "Timeline," Canadian Mental Health Association, 2019, <https://cmha.ca/100year/timeline>.

³⁸⁴ SARC, "Kinsmen School Opened in Estevan," *Outlook: Newsletter for the Saskatchewan Association of Retarded Children* (Saskatoon, December 1964).

³⁸⁵ Sydiaha et al., *A Question of Rights: Saskatchewan's Mentally Retarded People Move From Institutions to the Community*. P. 11.

³⁸⁶ Leslie Baker et al., "Deinstitutionalisation Postcards," *After the Asylum*, 2019, <https://aftertheasylum.apps01.yorku.ca/deinstitutionalization-postcards/>.

regions.³⁸⁷ In 1961, the Mental Hygiene act was replaced by the Mental Health Act, which made it more difficult to involuntarily institutionalise people.³⁸⁸ With the use of new medical treatments, new forms of care delivery, and relaxed mental health legislation, the institutionalised population began to decline.³⁸⁹ Furthermore, it was not just mental health asylums that were losing patients. Due to medical advancements, sanatoriums for the treatment of people who had tuberculosis were also closing their doors.³⁹⁰ Still, Saskatchewan's economic reliance on institutionalisation remained in place.

With less ability to focus on people who have mental illness, social problems such as alcoholism, or communicable disease, the Government of Saskatchewan began to concentrate more on the provision of institutional care for people who have intellectual disability. The attention after 1955 was on training schools with the goal that people who had intellectual disabilities would be trained to live and thrive within the community. Ever expanding their use of institutional facilities to foster economic growth, in 1961 the Government of Saskatchewan opened an additional 310 bed Saskatchewan Training School campus in Prince Albert.³⁹¹ This event happened for two reasons. The first reason was that the Moose Jaw Facility was already above capacity and had a lengthy waiting list.³⁹² The second reason was that the Prince Albert Sanatorium was closing, but the institutional facility was important to the Prince Albert economy.³⁹³

³⁸⁷ Baker et al.

³⁸⁸ Ministry of Social Services, "Appendix D: History of Mental Health and Addictions Services in Saskatchewan." P. 19

³⁸⁹ Ministry of Social Services. P.19.

³⁹⁰ Sydiaha et al., *A Question of Rights: Saskatchewan's Mentally Retarded People Move From Institutions to the Community*. P.11.

³⁹¹ Sydiaha et al.P. 11.

³⁹² Sydiaha et al. P. 11.

³⁹³ Sydiaha et al. P. 11.

Although Saskatchewan already had the highest number of training school beds per capita in Canada, in 1968 there were plans proposed to open an additional training school on the grounds of the Weyburn Mental Hospital.³⁹⁴ This was meant to mitigate the effects of the impending closure of the Weyburn Mental Hospital in 1971, which was viewed as an economic crisis by the local residents.³⁹⁵ Unable to justify further institutional spaces for people who have intellectual disability, the Government of Saskatchewan chose to repurpose the buildings to become an 82-bed regional psychiatric centre, and the Souris Valley Extended Care Hospital.³⁹⁶ Medical doctors and psychologists may have been already been long convinced that community care was best, but the economic reliance on institutionalisation prolonged the use of institutional facilities for decades to come.

The second opening of the policy window occurred in the late 1960s and early 1970s when the medical and social reasons for institutionalisation became insupportable. Eugenics, the ideology that underpinned much of institutionalised care, had fallen out of favour in the scientific and medical communities, and community-based care was already accepted as the best practice. In addition, the Saskatchewan Training School had become the site of some embarrassing scandals concerning the ineffectiveness of the training program. For example, the STS was thought to be understaffed as the staff/resident ratio was reported to be 1:7 during the day, and 1:15 during the evening.³⁹⁷ Furthermore, the staff shortage made it difficult to provide anything beyond custodial care. Although the mandate of the institution was to provide therapeutic

³⁹⁴ Sydiaha et al. P. 12.

³⁹⁵ Sydiaha et al. P. 12.

³⁹⁶ Ministry of Social Services, "Appendix D: History of Mental Health and Addictions Services in Saskatchewan."

³⁹⁷ Sydiaha et al., *A Question of Rights: Saskatchewan's Mentally Retarded People Move From Institutions to the Community*. P. 15.

training to the residents, there were very few therapists employed.³⁹⁸ This resulted in only a very few residents receiving therapy, while the majority of residents had very little or no programming at all.³⁹⁹ Even when residents were deemed “rehabilitated” and ready to be returned to the community, the community was unwilling and unable to accept them.⁴⁰⁰ The STS was revealed as a failure, people everywhere were demanding de-institutionalisation, but the Government of Saskatchewan stayed on course.

By the 1970s, the international social movement for de-institutionalisation had achieved great success in transforming attitudes. The Government of Saskatchewan was already aware that that a policy of institutionalisation was no longer viable, and they had been made aware of this reality by various reports and studies that they had commissioned. The economic shift in attention from the institutionalisation of “mental defectives” to the rehabilitation and training of people who have intellectual disability was failing. In 1974, for example, a consultant hired by the Government of Saskatchewan determined that the services supplied by the STS had become obsolete just a few years after the facility had opened.⁴⁰¹ Ultimately, it took the increased availability of federal funding for the Government of Saskatchewan to begin investing in community structure in earnest.

Until Ottawa promised to share the costs of Saskatchewan’s health services, calls for the province to significantly expand community infrastructure went unheeded.⁴⁰² The federal funding came with conditions, however, but the Government of Saskatchewan was eager to obtain the money, which would cut their health spending in half.⁴⁰³ To receive the money, the

³⁹⁸ Sydiaha et al. P. 16.

³⁹⁹ Sydiaha et al. P. 16.

⁴⁰⁰ Sydiaha et al. P. 16.

⁴⁰¹ Sydiaha et al.

⁴⁰² Sydiaha et al. P. 18.

⁴⁰³ Sydiaha et al. P. 18.

Government of Saskatchewan was required to transform their programs for people who had intellectual disability.⁴⁰⁴ Specifically, Saskatchewan had to do more than simply: “[c]hange signs on the door”, and they had to prove that programs were: “[m]ore rehabilitative than custodial”.⁴⁰⁵ The Government of Saskatchewan satisfied Ottawa’s requirements by placing the “mental retardation program” under the direction of the Ministry of Social Services, which had a focus on services within the community.⁴⁰⁶ This was the birth of Core Services, which had the mandate to utilise community services whenever possible, and invested in community infrastructure that was first envisioned by the community, rather than the government.⁴⁰⁷ The result was a yearly transfer payment of \$3 million from the Canada Assistance Plan with the stipulation that: “[p]rogressive program development of services for the mentally retarded requires the development of community-based programs that allow the retarded a more normal, non-institutional life. ...There is a need for strengthened programs both within and outside the institution to achieve the above directives.”⁴⁰⁸

At the same time the director of research for the STS, Lorne Elkin, was publishing extensively on the benefits of de-institutionalisation, inclusion, and community care, and reporting on the shortcomings of the STS and the Valley View Centre.⁴⁰⁹ Due to advancements in health care and changes in attitudes, the STS required re-branding and re-purposing if it was to remain in use. This finally resulted in the Government of Saskatchewan changing the name of the facility to the Valley View Centre, and the re-organisation of the services that the institutional facility offered. This transition period marked the end of the era of

⁴⁰⁴ Sydiaha et al. P. 18.

⁴⁰⁵ Sydiaha et al. P. 18

⁴⁰⁶ Sydiaha et al.

⁴⁰⁷ Sydiaha et al. P. 18.

⁴⁰⁸ Sydiaha et al. P. 18.

⁴⁰⁹ Sydiaha et al.

institutionalisation, and the beginning of the era of de-institutionalisation. Just the same, the Valley View Centre remained open until 2019, continuing to serve as a major employer for Moose Jaw residents.

The third opening of the policy window came with the widespread rejection of welfare state economics. While the Welfare State was once a foundation of economic policy within a wide variety of liberal western democracies, many governments later chose to pursue privatisation. The Government of Saskatchewan appears to have come later to this project, as Great Britain under Thatcher, and the United States under Reagan, had already made great strides toward closing institutional facilities and privatising care during the 1980s. Yet, as we have seen, Saskatchewan was long resistant to abandoning an institution-based economy.

In Saskatchewan, the era of economic reform through privatisation began in 2007 with the election of Premier Brad Wall. Faced with an aged institutional facility that was unrealistic to repair, and that was no longer providing the best form of care, the Government of Saskatchewan was required, both ethically and due to their chosen economic policies, to pursue reforms. This meant that the Valley View Centre would need to finally close and that the Government of Saskatchewan would distance themselves from the direct care of people who have intellectual disability. Instead, a care-delivery marketplace was opened, which is intended to provide Saskatchewan people who have intellectual disability with a wide array of choices.

Each time the policy window opened; policy entrepreneurs took their opportunity to effect change. Passing through the first window, Premier Tommy Douglas and Attorney General Corman made a move to create social and economic conditions that they believed would be of benefit to the people of Saskatchewan. At the second window, during the 1960s and 1970s, academic and community calls for inclusion dominated the policy discussion, and the

opportunity provided by Ottawa's Canada Assistance Plan managed to finally turn policy decisions toward inclusive community care. Scholars such as Lorne Elkin pressed the Government of Saskatchewan to set aside the outdated policies that had been in service to the ideology of eugenics, and instead embrace inclusion and community care. It is notable that, if not for Elkin's position as director of research at the STS/Valley View Centre, his efforts may not have had the strong effect that they had. Finally, when the most recent policy window opened, Premier Brad Wall used his vision to improve the situation of Saskatchewan people who have disability and chose to invest in the long-needed infrastructure that would make the de-institutionalisation of people who have intellectual disability possible.

Saskatchewan's Economic Reliance on Institutionalisation: Tommy Douglas, Eugenics, and the Welfare State:

When Tommy Douglas worked with the residents of the Saskatchewan Hospital, he developed the strong conviction that people who have intellectual disabilities should be cared for separately from those who have mental health disorders.⁴¹⁰ While his convictions were influenced by both changing standards in medical practices and by his personal relationships with Saskatchewan Hospital residents, it is imperative to understand that Douglas also possessed a strong interest in eugenics. This interest was evident by Douglas's 1933 Master of Arts thesis in sociology from McMaster University, which was entitled: "The Problems of the Subnormal Family".

Within his thesis, Douglas argued that the State, the School, and the Church, each had a role in limiting the negative effects to society that were caused by the influence of "subnormal

⁴¹⁰ Wickham, "Valley View Centre Heritage Report." p. 1-2.

families”.⁴¹¹ Subnormal families were defined by Douglas as being: “[a]nywhere from high grade morons to mentally defective, a family whose moral standards were below normal, ...who are delinquent, ...subject to social disease, and so improvident as to be a public charge”.⁴¹² According to Douglas, a subnormal family might include just one of these symptoms, a few of the symptoms, or all of them.⁴¹³ Not only does Douglas’s work imply that poverty is a result of being “mentally defective”, but Douglas claimed that such offspring are the product of moral impurity. Douglas did not come up with these ideas on his own, but rather, these ideas reflect the dominant social and scientific ideologies of his day.

Advocates for eugenics promoted scientific studies that: “[a]ttempted to calculate the risk and social cost of inheriting mental and moral defects”.⁴¹⁴ In support of this type of eugenics ideology, Douglas claimed that the subnormal family were a physical, mental, moral, and expensive detriment to society.⁴¹⁵ Subnormal families, according to Douglas, were responsible for spreading sexually transmitted infections, spreading contagious diseases, they were a drain on the public-school system, and dependent upon public funds for their financial support. The remedy for these ills, proclaimed Douglas, was to get the State, the schools, and the churches to work together to create legislation, and to provide services that would thwart the: “[e]ver increasing menace physically, mentally, and morally” that subnormal families were imposing upon society.⁴¹⁶

⁴¹¹ C T Douglas, “The Problems of the Subnormal Family,” *Sociology* (1933), <https://macsphere.mcmaster.ca/handle/11375/7736>. P. 1.

⁴¹² Douglas. P. 1.

⁴¹³ Douglas. P. 1

⁴¹⁴ Erika Dyck, *Facing Eugenics: Reproduction, Sterilization, and the Politics of Choice* (Toronto: University of Toronto Press, 2013).

⁴¹⁵ Douglas, “The Problems of the Subnormal Family.” P. 12

⁴¹⁶ Douglas. P. 20

Douglas further believed that it was the responsibility of the State to create legislation that was meant to curb the number of people who have intellectual disabilities from being born. To ensure that couples would not produce ‘mental defectives’ or pass disease onto their offspring, Douglas advised that marriage license applicants should produce a medical certificate of both physical and mental fitness before any marriage licence would be issued.⁴¹⁷ Furthermore, Douglas believed that such a measure would assist morally upright and healthy individuals from being deceived into marrying someone that was not mentally and physically fit.⁴¹⁸ An additional stop-gap policy proposed by Douglas was the establishment of a 7-day waiting period to receive a marriage license. Douglas believed that such a measure would prevent the elopement of unfit couples.⁴¹⁹ In 1933, the same year that Douglas completed his Master’s thesis, the Government of Saskatchewan had amended the Marriage Act to bar ‘idiots’, ‘imbeciles’, ‘sufferers of chronic mental disease’, and ‘sufferers of communicable disease’ from marriage.⁴²⁰

While Douglas hoped to restrict certain couples from marrying in the first place, he was aware that stricter policies surrounding marriage licences would not be enough to eliminate the formation of what he had defined as subnormal families. Therefore, Douglas called for a policy to segregate people who have intellectual disabilities from the larger society. Douglas reasoned that: “[s]ociety does not hesitate to segregate criminals, lepers, or any others that threaten the well-being of society. There can be little doubt that this group exercises an influence that is detrimental and could best be removed by segregating them”.⁴²¹ Douglas’s idea was not an

⁴¹⁷ Douglas. P.21

⁴¹⁸ Douglas. P. 21

⁴¹⁹ Douglas. P. 22

⁴²⁰ Dyck and Deighton, *Managing Madness: Weyburn Mental Hospital and the Transformation of Psychiatric Care in Canada*.

⁴²¹ Douglas, “The Problems of the Subnormal Family.” P. 24

original one and institutional facilities that were meant to segregate people who have intellectual disabilities had already existed within Canada for some time. For example, the Orillia Asylum for Idiots was opened in Ontario in 1876 and continued to operate until its closure in 2009.⁴²² The Orillia Asylum was only the first of 17 institutions operated by the Government of Ontario that were specifically meant to house and segregate people who have intellectual disability.⁴²³

It is necessary to remark that the ideas communicated within Tommy Douglas' thesis are fundamentally obsolete and generally considered distasteful by most people. Still, they were accepted mainstream ideas at the time that Douglas wrote them, especially in Western Canada, but also in the United States and European nations such as Great Britain and Germany. Different nations had different objectives. For example, British eugenicists were focused on class and poverty, while the United States were focused on racial differences.⁴²⁴ In Western Canada, eugenicists are thought to have combined the objectives of the British and the Americans, but with an added focus on intelligence and perceived parenting ability.⁴²⁵

Furthermore, there was a level of anxiety present that assisted the acceptance of eugenics programs. The Bureau of Social Research of the Governments of Manitoba, Saskatchewan and Alberta, for example, published a pamphlet in 1916 that warned of the increasing numbers of "mental defectives" present in the prairie provinces, and that certain steps should be taken to alleviate the perceived crisis.⁴²⁶ It might even be argued that the perceived British capability to manage social problems had an effect on the decisions of the western provinces to join the

⁴²² Ontario, "The First Institution," Ontario Ministry of Children, Community and Social Services, 2019, <https://www.mcscs.gov.on.ca/en/dshistory/firstInstitution/>.

⁴²³ Ontario.

⁴²⁴ Dyck, *Facing Eugenics: Reproduction, Sterilization, and the Politics of Choice*.

⁴²⁵ Dyck.

⁴²⁶ Sydiaha et al., *A Question of Rights: Saskatchewan's Mentally Retarded People Move From Institutions to the Community*. P. 9.

Dominion of Canada. When Saskatchewan built the large Weyburn Mental Hospital, it symbolised what has been described as a: “[b]eacon of order and a monument to civilisation”.⁴²⁷ The building of such monuments was an important component in the colonisation of the Canadian west.

Thus, as distasteful as Douglas’s thesis is today, eugenics was a mainstream ideology that was widely accepted by both the federal and provincial governments during the early 20th century. Specifically, policies concerning people who have intellectual disabilities were constructed to conform with many of the ideals of eugenics, and these policies were often considered progressive.⁴²⁸ Eugenics had become a strategy to assist Canadians in their nation building, and their path to colonisation of the west included the social engineering of the population. For instance, the Sexual Sterilisation Act (1928) of Alberta enabled the involuntary sterilisation of people who have intellectual disabilities, as well as various other people that the government believed should not have the ability to reproduce.⁴²⁹ As Douglas outlined within his thesis, governments believed that ‘mental defectives’ were both an economic strain on the public purse, and a danger to the population.

The Province of Alberta sterilised almost 2,822 children and adults before Alberta’s Sexual Sterilisation Act was repealed in 1972.⁴³⁰ Notably, as many as 4,725 people were recommended for sterilisation by Alberta’s eugenics board, and this group included people who experienced psychosis, people who had intellectual disability, people who had syphilis, people who had epilepsy, people who had Huntington’s disease, and children who had acquired brain

⁴²⁷ Dyck, *Facing Eugenics: Reproduction, Sterilization, and the Politics of Choice*.

⁴²⁸ A Deighton, “Saskatchewan,” Eugenics Archive, 2015, <http://eugenicsarchive.ca/database/documents/551482b25eff8d344d000001>.

⁴²⁹ David McConnell, “Parenting with Intellectual Disabilitie,” Eugenics Archive, 2014, <https://eugenicsarchive.ca/discover/connections/535eed3e7095aa0000000245>.

⁴³⁰ McConnell.

injury.⁴³¹ While Alberta had taken responsibility for the care of existing people whom they labelled as mental defectives, the plan was to prevent further such people from being born.

Saskatchewan unsuccessfully attempted to pass their own sterilisation law. A coalition government, comprised of both progressives and conservatives, designed a sterilisation bill as a part of their healthcare policy agenda.⁴³² Although the sterilisation bill passed first reading with only one dissenting vote, it failed to become law before the coalition government collapsed in 1930.⁴³³ The succeeding government is believed to have rejected the bill due to growing Roman Catholic opposition to sterilisation.⁴³⁴ The Government of Saskatchewan did, however, manage to pass the 1930 Mental Defectives Act, that enabled people to be judged ‘mentally defective’ by a Justice of the Peace, and then be committed to institutional facilities.⁴³⁵ Many people that were classified as a mental defectives were sent to the Weyburn Mental Hospital where they underwent psychiatric treatments such as insulin therapy, hydrotherapy, lobotomy, electroshock therapy, and ‘work and water treatment’ where people who failed to respond to hard labour were subjected to ice baths.⁴³⁶

When the Weyburn Mental Hospital opened in 1921, it housed 900 patients that were cared for by 60 nurses and an additional 60 attendants.⁴³⁷ A second wing was soon constructed that allowed room for 3000 patients and staff, and then a third wing was constructed by 1929 that

⁴³¹ Dyck, *Facing Eugenics: Reproduction, Sterilization, and the Politics of Choice*. P. 3.

⁴³² Alex Deighton, “Saskatchewan,” Eugenics Archive, 2015, <http://eugenicsarchive.ca/database/documents/551482b25eff8d344d000001>.

⁴³³ Deighton.

⁴³⁴ Deighton.

⁴³⁵ Deighton.

⁴³⁶ Colette Leung, “Weyburn Mental Hospital,” Eugenics Archive, accessed October 16, 2019, <http://eugenicsarchive.ca/discover/institutions/map/519b32ec4d7d6e000000000b>.

⁴³⁷ Soo Line Historical Museum, “Weyburn Mental Hospital.”

provided room for an additional 400 patients.⁴³⁸ Despite this rapid expansion, the Weyburn Mental Hospital was perennially over capacity.⁴³⁹ One employee described the situation:

It was so crowded that we had to set up beds in the dining room and perhaps we could put a hundred beds in each dining room. In the dormitories, it was so crowded that we couldn't walk between the beds, so we had to walk on top of the beds. We would go from one bed to another to wake the patients in the morning.⁴⁴⁰

Due to the overcrowding, the Weyburn Mental Hospital served as a custodial care facility for people who had intellectual disabilities and mental illnesses. In this context, custodial care refers to the inability of staff to provide more than the most basic of services. One former employee explained that: “all you could do was manage the baths and feeding, and management of behaviour”.⁴⁴¹ Therefore, life at the Weyburn Mental Hospital was merely incarceration for many residents, serving to segregate the residents from the larger population. Many residents did not even require medical therapies. A former Weyburn Mental Hospital employee described that: “[t]his was also a shelter for the underprivileged, the unwanted, because it's a government institution. They had no other place to go so they came here”.⁴⁴² Another former employee stated that:

There were people admitted here that actually weren't psychotic that might have had some difficulty with their family or difficulty with society, but somebody would swear a commitment with a judge, and that individual would be admitted and then they would get institutionalised and they would stay for a long time. It really was a catch all place because you had people with mental illness like depression and schizophrenia, but the mentally handicapped came here, alcoholics were sent here, epileptics. People with epilepsy that didn't have a whole lot of other problems—they were sent here.⁴⁴³

⁴³⁸ Soo Line Historical Museum.

⁴³⁹ Soo Line Historical Museum.

⁴⁴⁰ Richard Diener and Steve Wolfson, *Weyburn: An Archaeology of Madness* (Canada: 3rd Eye Media Productions, 2004), https://www.imdb.com/title/tt1438284/videoplayer/vi2743599641?ref_=tt_ov_vi.

⁴⁴¹ Soo Line Historical Museum, “Weyburn Mental Hospital.”

⁴⁴² Diener and Wolfson, *Weyburn: An Archaeology of Madness*.

⁴⁴³ Diener and Wolfson.

It should not be overlooked that during the 1940s and 1950s, Saskatchewan had Canada's highest population per capita of institutionalised residents.⁴⁴⁴ During the Depression of the 1930s, the Government of Saskatchewan faced strong pressure to institutionalise growing numbers of people.⁴⁴⁵ The 1930 Mental Defectives Act enabled the Government of Saskatchewan to categorise and then institutionalise a widening range of people.⁴⁴⁶ Keeping in mind that it was generally believed that low morals, criminality, and poverty were the result of mental deficiency, this meant that anyone at all who perceived to be suffering from low intelligence was eligible for institutionalisation.

The Weyburn Mental Hospital would also accept unwanted children. A former employee acknowledged that: "[w]e actually admitted children here and there is some historical information that some children stayed here for 20-30 years".⁴⁴⁷ Gordon Smith was one of these children and he was admitted to the institutional facility at the age of 9. After being left at the Weyburn Mental Hospital by a relative, Mr Smith recalled that:

My Dad died. About three years later my mother said she was getting married. I said I couldn't figure out who she could be marrying. There is only this old carpenter guy coming around once in a while. She says well that's the guy. He said that these kids have got to go. She said either they go or he goes. So, my one sister went and lived with her grandmother, and then it was a week later they said that I'm going to the Weyburn area with some boys on a farm and horses and stuff like that. So, my grandmother brought me out here July the 5th, 1944. It was Wednesday and raining out. Well, they came back a year later and said hello again, you know.⁴⁴⁸

⁴⁴⁴ Soo Line Historical Museum, "Weyburn Mental Hospital."

⁴⁴⁵ Dyck and Deighton, *Managing Madness: Weyburn Mental Hospital and the Transformation of Psychiatric Care in Canada*.

⁴⁴⁶ Dyck and Deighton.

⁴⁴⁷ Diener and Wolfson, *Weyburn: An Archaeology of Madness*.

⁴⁴⁸ Diener and Wolfson.

Entrance into the Weyburn Mental Hospital could be frightening, and patients appear to have had little control over their fate. A former Weyburn Mental Hospital employee described the daunting process of admissions:

When the new patient was admitted, we would have a panel discussion and decide what unit he should go on. So, the poor guy would sit in the centre and one psychiatrist would say “oh I think I can’t get anything out of him, he must be an idiot”. Another psychiatrist would say “no I heard him. He said two or three sentences and he made some sense”. Oh, then they all agreed he was a moron.⁴⁴⁹

Gordon Smith’s experience of admission to the Weyburn Mental Hospital illustrates a similar experience of staff medicalising his behaviour. Mr Smith stated that: “[t]here is this one time there I was about 10 or 12. I don’t know if they were doctors or who they were, and they’re reading off all this stuff and none of it made any sense to me. They said that I played with dolls and or whatever, eh? But on our block, all there was was girls!”.⁴⁵⁰ Not only were unwanted children such as Gordon Smith consigned to the strict rules of institutionalised life, but their options for development were few. For example, few of the institutionalised children were given access to education. Gordon Smith reported that: “[g]oing to school was the only really enjoyable thing that I did there. ...There wasn’t that many that went to school because they didn’t know what was going on”.⁴⁵¹ Even the activities of children that were not classified as having an intellectual disability, however, were highly restricted. Gordon Smith recalls that:

When you are out in the yard at recess, you could go to the ball diamond, but you don’t go beyond the ball diamond. I like to see what’s beyond, its just normal, eh? So, I went up in a tree and I was looking at a bird, eh? And there were some Robin’s eggs, eh? And the teacher. She was mean. I don’t know why she was mean. She called administration and said I had gone across the road and I am not supposed to go across the road. So that is when they put me down in 2A, the snake pit, for two months, eh? There was absolutely no one to talk to and the patients just pooped on the floor

⁴⁴⁹ Diener and Wolfson.

⁴⁵⁰ Diener and Wolfson.

⁴⁵¹ Diener and Wolfson.

and peed on the floor and they had this here (patient) who came from another floor to clean up the mess because no one wanted to clean up that mess. And he would sing a tune when he cleaned it. It was all he ever said. The smell was terrible. It was like staying on a farm in a pen that had never been cleaned out, eh?⁴⁵²

Severe punishment such as that described by Gordon Smith was commonplace at the Weyburn Mental Hospital. Former employees report that: “[w]e did have rooms in the basement where if people got aggressive, they would go in and there was a sliding glass peephole so the staff could look in. Much like you see in Alcatraz”.⁴⁵³ Former employees also report that: “[p]eople that were violent were given electric shock treatments. We used shock treatment once a day for 5 to 10 days and it subdued him”.⁴⁵⁴ Shock treatment did not always work to subdue difficult patients and sometimes more severe measures were pursued. Former employees admit that: “[i]f you had an extremely violent patient they were lobotomised. They calmed right down. I think what they lost was their emotions”.⁴⁵⁵

While the form of medical treatment at the Weyburn Mental Hospital was punitive and largely focused on custodial care, there were few options available at the time. Former employees admit that the treatments they provided for mental illness did not appear to have any effect.⁴⁵⁶ Electric shock therapy was believed to treat mania, catatonia, schizophrenia, and other mental illnesses, but their effect was simply that patients would experience memory loss and confusion.⁴⁵⁷ In 1937, insulin therapy was introduced for use on patients who had psychosis, drug addiction, and schizophrenia. The process of insulin therapy was to inject the patient with insulin, which would cause hypoglycaemia, which in turn caused the patient to experience

⁴⁵² Diener and Wolfson.

⁴⁵³ Diener and Wolfson.

⁴⁵⁴ Diener and Wolfson.

⁴⁵⁵ Diener and Wolfson.

⁴⁵⁶ Diener and Wolfson.

⁴⁵⁷ Soo Line Historical Museum, “Weyburn Mental Hospital.”

epileptic seizures until they finally entered a coma.⁴⁵⁸ Then, the patient would be injected with glucose.⁴⁵⁹ As well, as many as 40 patients per day were treated with hydrotherapy, which consisted of the patients being wrapped with ice cold wet sheets that were meant to cause the patient to go into hypothermia. Once the patient was calm, the sheets would then be removed.⁴⁶⁰ Another method of hydrotherapy included strapping patients into bathtubs, sometimes for days, while alternating hot and cold water would continuously run.⁴⁶¹

Occupational therapy was an important treatment utilised at the Weyburn Mental Hospital, and included activities such as knitting, crocheting, embroidery, rug making, basket weaving, woodworking, broom making, pottery, and painting.⁴⁶² Occupational therapy also took place in workshops where patients could learn marketable skills.⁴⁶³ For example, Gordon Smith was taught how to repair watches.⁴⁶⁴ Other patients were involved in farming, maintaining buildings, and in resident care.⁴⁶⁵ Former employees report, however, that: “[s]ome people got good at their jobs. I know somebody that was out of there (Weyburn), and they had 500 pigs and some chickens. They got good at it out there. Well, they’re a little reluctant to discharge him, you know”.⁴⁶⁶

Hard work, strict corporal punishment, and ineffective medical therapies were combined with sexual assault and physical abuse. Many of the patients at the Weyburn Mental Hospital were confined to locked wards where the conditions were dreadful. A former employee recounts that: “[m]y first memory is really just coming in and wondering why the patients weren’t

⁴⁵⁸ Soo Line Historical Museum.

⁴⁵⁹ Soo Line Historical Museum.

⁴⁶⁰ Soo Line Historical Museum.

⁴⁶¹ Soo Line Historical Museum.

⁴⁶² Soo Line Historical Museum.

⁴⁶³ Soo Line Historical Museum.

⁴⁶⁴ Diener and Wolfson, *Weyburn: An Archaeology of Madness*.

⁴⁶⁵ Soo Line Historical Museum, “Weyburn Mental Hospital.”

⁴⁶⁶ Diener and Wolfson, *Weyburn: An Archaeology of Madness*.

wearing clothes and why there were so many people all in one place.”⁴⁶⁷ Another employee remembers that:

I came in 1964 and of course that was the year that I graduated from high school and I was quite interested in this psychiatric nursing. I thought “Oh Wow, this is really something”, and I thought that I was going to help all these people so I came here to Weyburn. I always said that if I had a means to leave after that first day that I went onto a unit, I probably would have left. The first unit that I worked on was in the basement and to get there I had to walk through another unit where the severely mentally handicapped people lived, and of course on that unit they were all males. Half of them were naked and they were lying around on the floor and I mean there was urine and whatever else around and I was carrying this big key and had to get into the unit on the other side. And to get through that unit was like “am I going to get through that unit alive?” You know you would look around and there were men following you. Men with no clothes on. It was pretty traumatic.⁴⁶⁸

Sexual assault was a reality for the patients. Gordon Smith describes his experiences as a vulnerable 9 year old child:

I got put into a ward for newcomers and all it was spittoons on the floor and tobacco butts laying all over and I’m thinking “What am I doing here?” There’s no kids here, nothing like that. This one guy came up to me with a white coat on and he says to me “you have to do what we tell you to do from now on. We’re like your parents. This is your home. So, you do what we say and everything will be fine”. My bed was right here. This is where my bed was. Within the first five days--it was sort of like a hospital ward--anyway you are sort of in bed and all of a sudden these guys, they start running their hands over you under the cover. “What the heck’s going on here?” The perverts. Then you realise the whole place is loaded down with paedophiles, but they had no name for them. I just knew that I never had anybody bothering me before and I didn’t know about oral sex and all that, but I sure had enough of that, eh? Okay? I’d say I had oral sex at least three or four times a week and that’s for the whole time, eh? I mean what’s a 10-year-old going to do with someone that weighs 200 lbs? You can’t do nothing.⁴⁶⁹

⁴⁶⁷ Soo Line Historical Museum, “Weyburn Mental Hospital.”

⁴⁶⁸ Diener and Wolfson, *Weyburn: An Archaeology of Madness*.

⁴⁶⁹ Diener and Wolfson.

Gordon Smith alleges that in addition to being sexually assaulted by fellow patients, that he was sexually assaulted by members of the Weyburn staff. After he was released upon reaching adulthood, Mr Smith reported the culture of sexual assault to the RCMP and confronted the staff members that were involved: “[t]he Spring of ’53 is when I set it all up. I said the RCMP should be here, but not in uniform, and I’d like to be able to pick out some choices for these here people. They either quit, they get fired, or they get charged”.⁴⁷⁰ When presented with the three choices, the accused staff members chose to immediately resign.⁴⁷¹ Gordon Smith appeared satisfied with the outcome and described the accused staff members as “[t]he men who would never apologise, eh?”.⁴⁷²

Although patients and staff have described life at the Weyburn Mental Hospital as horrific, this institutional facility was typical and at the forefront of medical care and research. Not only was the field of psychiatric nursing developed in Saskatchewan, but the Weyburn Mental Hospital became famous for advancements in psychiatric research.⁴⁷³ In 1946, Premier Douglas appointed Dr Griff McKerracher commissioner of mental health services, who worked to establish a psychiatric research program within Saskatchewan. By 1951, the Weyburn Mental Hospital had attracted Dr Humphry Osmond, who was notable for his theories regarding chemical imbalance in the brain as the cause of schizophrenia.⁴⁷⁴ Additionally, Dr Osmond pioneered research related to the use of hallucinogens in psychiatric treatment.⁴⁷⁵ A former employee stated that:

⁴⁷⁰ Diener and Wolfson.

⁴⁷¹ Diener and Wolfson.

⁴⁷² Diener and Wolfson.

⁴⁷³ Erika Dyck, *Psychadelic Psychiatry: LSD from Clinic to Campus* (Saskatoon: JHU Press, 2008). P. 25

⁴⁷⁴ Moheb Costandi, “Looking Back: A Brief History of Psychedelic Psychiatry,” *The Psychologist* 27, no. September (September 2014), <https://thepsychologist.bps.org.uk/volume-27/edition-9/looking-back-brief-history-psychedelic-psychiatry>.

⁴⁷⁵ Costandi.

Dr Osmond was very interested in research and he also knew how to get money and convinced the politicians that this is what was needed to be done. It did attract doctors from all over the world. You know, people from the Menninger Clinic were here and sociologists from other countries—and researchers were here—and it was a very promising time to work here. There is a research department in the basement that had test tubes and microscopes just like you see in the movies. There were PhD psychologists and other medical individuals whose sole job was to do research.⁴⁷⁶

Soon after arriving at the Weyburn Mental Hospital, Dr Osmond began to work with Dr Abram Hoffer, embarking on a project that would make Saskatchewan: “[h]ome to the largest LSD experiments in the world”.⁴⁷⁷ It was at the Weyburn Mental Hospital where Dr Osmond coined the word ‘psychedelic’ to describe the effects of LSD, and where several studies on the therapeutic uses for LSD in the treatment of schizophrenia and alcoholism took place.⁴⁷⁸ These experiments were endorsed by Premier Douglas, his socialist Cooperative Commonwealth Federation party, and the general public.⁴⁷⁹ Premier Douglas had committed to situating Saskatchewan as a medical research centre that would complement the innovation of Saskatchewan’s healthcare system.⁴⁸⁰ Evidently, efforts were rewarded as Dr Osmond published 13 research papers in 1959, and 17 more research papers in 1960.⁴⁸¹ With major contributions to the scientific literature, the ability to attract researchers and research funding from organisations such as the Rockefeller Foundation, the Ford Foundation, and the Squibb corporation⁴⁸², Saskatchewan’s strategy to become a major medical research centre succeeded.

⁴⁷⁶ Diener and Wolfson, *Weyburn: An Archaeology of Madness*.

⁴⁷⁷ Dyck, *Psychadelic Psychiatry: LSD from Clinic to Campus*.

⁴⁷⁸ Dyck. P. 11.

⁴⁷⁹ Dyck. P. 11.

⁴⁸⁰ Dyck. P. 11.

⁴⁸¹ Soo Line Historical Museum, “Weyburn Mental Hospital.”

⁴⁸² Dyck, *Psychadelic Psychiatry: LSD from Clinic to Campus*. P.11

In the eyes of the Government of Saskatchewan, the policy of institutionalisation was a success. There were benefits to the economy, people perceived as mental defectives were out of sight and under control, and Saskatchewan had become world famous for advancement in the treatment of mental illness. Both the Weyburn Mental Hospital and the North Battleford Insane Asylum were bursting at the seams and medical knowledge about caring for people who have intellectual disability continued to evolve. Long on his agenda, Premier Douglas wanted to realise his goal of caring for people who have intellectual disability separately from people who have mental illness. There was also the idea that people who have intellectual disability could be trained to become employable and thus contribute to society. Based on these issues, the Government of Saskatchewan determined that an additional large institutional facility should be built. One that was dedicated to the care and training of people who had intellectual disability. This planned facility would become the Saskatchewan Training School, and people across Saskatchewan desired that it should be built near their community so that they would reap the economic benefits.

The establishment of an institutional facility was widely believed to be a boon to the economy, and there is good reason why many Saskatchewan cities competed to have the Saskatchewan Training School built in their region. Taking the example of the Weyburn Mental Hospital, the extent of economic stimulus is obvious. A newspaper report described the scale of the project as:

Nearly a thousand cars of material were required for the building. A total of 4,294,000 bricks were used, with 1,298,000 feet of rough lumber, and 278,000 hollow tiles. There is a total of 257,500 square feet of floor area, of which 101,000 is maple and 156,500 cement or terrazzo floor. Thirteen hundred tons of steel were used for the frame. The total cost of the building is slightly over \$2,250,000 exclusive of the furniture and fittings.⁴⁸³

⁴⁸³ Soo Line Historical Museum, "Weyburn Mental Hospital."

Not only did the initial construction of the buildings provide many jobs for local workers and businesses, but the construction had only just begun. After the Weyburn Mental Hospital opened, work immediately started on the second wing, and by 1929, a third wing had been constructed.⁴⁸⁴ Many outbuildings were constructed, such as the farm, the power plant, a greenhouse, and more.⁴⁸⁵ By 1937, an annex was built to house the many patients that had contracted tuberculosis.⁴⁸⁶ In addition to this, construction workers would be kept busy with demands for increased civil infrastructure, housing and commercial development within the city of Weyburn, providing ample work to last for many years.

The Weyburn Mental Hospital also required many employees and psychiatric nursing became a common career choice amongst the residents of Weyburn.⁴⁸⁷ As well, there were many other jobs made available to Weyburn residents, and these positions required administration staff, cooks, bakers, a butcher, various types of domestic staff, orderlies, maintenance workers, power plant engineers, farmhands, occupational therapists, medical assistants, X-ray technicians, medical doctors, psychologists, and much more.

In 1950, it was reported that the kitchen was preparing 7,500 meals per day, including staff meals.⁴⁸⁸ The institutional facility also managed to claw back funds by charging the employees room and board, and in 1955, resident nurses paid \$35.00 per month for a bed and three meals per day. Simply to keep the patients fed and warm, the Weyburn Mental Hospital was required to make large purchases of fuel and food, and they purchased upwards of 100,000

⁴⁸⁴ Soo Line Historical Museum.

⁴⁸⁵ Soo Line Historical Museum.

⁴⁸⁶ Soo Line Historical Museum.

⁴⁸⁷ Soo Line Historical Museum.

⁴⁸⁸ Soo Line Historical Museum.

gallons of water per day from the City of Weyburn⁴⁸⁹. Therefore, the presence of a large institutional facility such as the Weyburn Mental Hospital provided much in the way of business and work opportunity for the local residents, and the government reaped the benefit of a thriving economy. Additionally, the more institutional facilities built, the wider the economic growth.

⁴⁸⁹ Soo Line Historical Museum.

Chapter 5

Saskatchewan's Social Movement for Inclusion

Through collective effort, Saskatchewan's social movement for inclusion has improved social conditions for those with intellectual disability. At the forefront of this social movement for inclusion, Inclusion Saskatchewan is one of the oldest formal advocacy organisations for people that have intellectual disability. Celebrating their 60th anniversary in 2016,⁴⁹⁰ Inclusion Saskatchewan's accomplishments have ranged from the creation of special education programs for children to the development of income support programs for adults. Although they have experienced many instances of success, in 2019, Inclusion Saskatchewan achieved one of their long sought-after goals. This goal was to achieve the permanent closure of the Valley View Centre in Moose Jaw, and to see the remaining Valley View residents de-institutionalised and transitioned to life in the community.

In pursuit of this goal, individuals and organisations worked collaboratively to ensure that the Government of Saskatchewan would create the necessary community infrastructure required to transition Valley View residents. On May 4th of 2009, Inclusion Saskatchewan, the Valley View Centre Family Group, and People First of Saskatchewan met to discuss the potential closure of the Valley View Centre. Facilitated by Inclusion Saskatchewan, Gregg Cochlan of the Pacific Institute was brought in to mediate the discussion, and to help the group members to move forward. During the meeting, each of the three groups shared their points of view with one another and discussed the issues. Although they had some conflicting ideas about how to get there, the three groups agreed they shared an identical goal. This goal was to see the Valley View Centre close, and that each Valley View resident must have a facilitated transition with

⁴⁹⁰ SACL, "Annual Report 15/16" (Saskatoon, 2016).

individually planned options for support. Additionally, the three groups agreed that a successful closure required that family members, former Valley View residents, peer supporters, and advocates would have a role in the decision making.

After achieving a consensus, Inclusion Saskatchewan petitioned the Government of Saskatchewan to make a commitment to closing Valley View Centre and to allow the stakeholders to develop a closure plan that included personal transition plans for each Valley View resident. This request was repeated for years before the government acted, but importantly, under the leadership of Inclusion Saskatchewan, the social movement for inclusion was addressing the situation with a collective voice. Eventually, the Government of Saskatchewan cooperated with Inclusion Saskatchewan and agreed to use a citizen participation model that allowed inclusion advocates to collaboratively construct new policies that would benefit people who have intellectual disability.

Collaboration was not easy for the advocates due to historical disagreements within the social movement for inclusion. Some organisations and individuals had differing points of view regarding de-institutionalisation and how to achieve community inclusion goals, and these debates were occurring internationally, and not just in Saskatchewan. As an organisation, Inclusion Saskatchewan has traditionally valued and used methods of collaboration with the Government of Saskatchewan, the Saskatchewan Teacher's Federation, local service groups and the community, but were also for a time believed by some inclusion advocates to have lost their way. Contemporary inclusion advocates now generally agree that some of the adversarial methods adopted by Inclusion Saskatchewan had harmed their relationship with the Government of Saskatchewan and others. Ultimately, however, Inclusion Saskatchewan returned to their roots

and healed broken relationships, and these efforts led Inclusion Saskatchewan to succeed in their goal of permanent closure of the Valley View Centre institutional facility.

Notably, Inclusion Saskatchewan, and the organisations that they collaborated with, achieved a success that has been elusive in the closure of other institutional facilities. The success of Inclusion Saskatchewan and the work of the Valley View Centre Transition Steering Committee are instrumental in understanding how de-institutionalisation is achieved. Part of the reason the inclusion advocates successfully managed the closure of the Valley View Centre and the transition of Valley View residents to the community was due to their dedication to the values of inclusion and their commitment to the personal needs of the Valley View residents. Not to be discounted, however, is how their success is due to the inclusion activists' willingness to work collaboratively with other organisations to create positive change.

Effecting Change from the Grassroots:

Over six decades, Inclusion Saskatchewan evolved from a small group of parents that were frustrated with their children's inability to attend school, to become the main advocate for Saskatchewan citizens who have intellectual disability. As they are driven by the needs of their members and the people they support; Inclusion Saskatchewan continues to describe themselves as a grassroots organisation.⁴⁹¹ Currently, Inclusion Saskatchewan provides support for approximately 3000 individuals and families throughout Saskatchewan.⁴⁹²

The name of the organisation has changed several times to reflect contemporary ideologies and attitudes toward recognised best practices in care. In 1957, the name of the organisation became the Saskatchewan Association for Retarded Children (SARC), but to be inclusive of all people with an intellectual disability, in 1969 the organisation's name was

⁴⁹¹ Kevin McTavish, "Interview Notes" (Saskatoon, 2017).

⁴⁹² Inclusion Saskatchewan, "About US," [inclusionsk.com](https://www.inclusionsk.com/about), 2019, <https://www.inclusionsk.com/about>.

changed to the Saskatchewan Association for the Mentally Retarded (SAMR). When de-institutionalisation became a dominant focus in the social movement for inclusion, the organisation's name was changed again in 1988 to the Saskatchewan Association for Community Living (SACL). Recently, the organisation changed its name in June 2018 to Inclusion Saskatchewan (INSK).⁴⁹³

Each name change has reflected the dominant issues important to inclusion advocates, as well as the changing roles of the organisation. The original group of parents who styled themselves as SARC were motivated to achieve access to education and other supports for their children and themselves. Later, SAMR became involved in issues of social justice that they believed would improve the situations of all people who have intellectual disability. As the international social movement for de-institutionalisation gained prominence, SAMR expanded their mission to adopt the ideals of de-institutionalisation and then strongly advocated for the closure of institutional facilities, changing their name to SACL. Currently, INSK is recognised as the main advocate for Saskatchewan persons who have intellectual disability, and now enjoys a functional working relationship and advisory role with the Saskatchewan Ministry of Social Services (MSS). Although there have been many name changes throughout its history, the primary motivation of the organisation has been the inclusion of persons that have intellectual disability, and this vision of inclusion has underpinned all the activity of the organisation.

The dissemination of information and the promotion of inclusive values have always been a mandate of the organisation, and these tasks have been facilitated through the organisation's official publications. The original newsletter of the organisation was named "Outlook", which eventually became named "Dialogue", and then eventually became a magazine

⁴⁹³ Britt Baumann, "Direct Observation Notes," n.d.

named “Dialect”. The Outlook and the Dialogue publications regularly reported on medical achievements concerning the treatment and prevention of conditions such as phenylketonuria and rubella, and they would summarise conference proceedings concerning trends in the care of people that have intellectual disability. The newsletters additionally provided information for parents about books they might be interested in reading, and any educational seminars parents might want to attend. Importantly, the organisation’s newsletters and magazines have served to connect families and assist them in sharing and obtaining resources for their loved ones. As it remains today, the original focus of the organisation’s official publication is centred on the promotion of inclusive education and inclusion in the community, as well as the dissemination of information about intellectual disability and caring for individuals who have intellectual disability.

Inclusion Saskatchewan’s mission is to “[e]nsure that citizens of Saskatchewan who have intellectual disabilities are valued, supported, and included members of society, and have opportunities and choices in all aspects of life”.⁴⁹⁴ Although this mission statement may not have been so efficiently crystallised in the earliest days of the organisation, early issues of Outlook and Dialogue promote these same ideas, meaning that the overall mission of Inclusion Saskatchewan has been constant throughout its existence.

To support their mission, Inclusion Saskatchewan promotes three concepts that emphasise the philosophy of inclusion for persons experiencing intellectual disability. These concepts are:

Citizenship: having their rights and freedoms respected and protected, but also having the opportunity to meet their obligations as participating and contributing citizens;

⁴⁹⁴ SACL, “Annual Report 15/16.”

Membership: belonging to families, friends, and neighbourhoods, with full inclusion in schools, places of work, and the community as a whole;

Determination: having an active and decisive voice in decisions, which affect their lives.⁴⁹⁵

The concepts of citizenship, membership, and determination permeate all elements of the social activism performed by Inclusion Saskatchewan, and the organisation adheres to the ethic that true inclusion means more than people being physically present in the community, rather than isolated in institutional facilities. Instead, Inclusion Saskatchewan works to ensure that persons experiencing intellectual disability will have: “[d]irect and significant participation in the community. ... This means that individuals will interact inclusively, socialise as a member of the community, and have a choice in residential housing, education, and work options”.⁴⁹⁶

The organisation has long focused on social justice for people who have intellectual disability. For example, in 1975, the organisation campaigned for an amendment to the Criminal Code of Canada that was judged to unfairly penalise persons that have an intellectual disability.⁴⁹⁷ The organisation’s call for change arose from their realisation that persons who were accused of a crime could be declared unfit to stand trial due to intellectual disability, and then sent to an institutional facility for an indefinite period of time, perhaps permanently.⁴⁹⁸ The organisation believed this process was unjust, and that the rights of persons experiencing intellectual disability were being infringed upon. Therefore, the organisation petitioned that people with intellectual disabilities would receive their right to a fair trial, and if found guilty, not to be penalised for that crime beyond the sentence that a typical offender would receive for

⁴⁹⁵ SACL, *Statement of Beliefs and Positions on Social Issues* (Saskatoon: Saskatchewan Association for Community Living, 2016).

⁴⁹⁶ SACL.

⁴⁹⁷ SAMR, “SAMR Wants Law Changed,” *Dialog: Newsletter of the Saskatchewan Association for the Mentally Retarded* (Saskatoon, December 1975).

⁴⁹⁸ SAMR.

the same offence.⁴⁹⁹ Today, Inclusion Saskatchewan continues to maintain a focus on judicial issues and will advocate for persons experiencing intellectual disability that may have been treated unjustly.⁵⁰⁰

Despite the improvements in social justice that have occurred over the last several decades, Inclusion Saskatchewan remains very busy. Current executive director Kevin McTavish has stated that: “[i]f everybody was fully valued and treated with respect, we wouldn’t exist”.⁵⁰¹ Throughout the 60 year history of the organisation, Inclusion Saskatchewan has supported the needs of the people they advocate for to access inclusive education and to find and keep employment.⁵⁰² As well, Inclusion Saskatchewan works with provincial ministries to design programs such as self-directed funding, which allows persons experiencing disability to make their own choices about where they will live and what services they will hire.⁵⁰³ Since they have always been focused on important social issues, Inclusion Saskatchewan continues to be a strong proponent for de-institutionalisation, and have lately been engaged in the medically assisted dying debate as it relates to people who have intellectual disability.⁵⁰⁴

Although exact numbers change from year to year, approximately 33% of Inclusion Saskatchewan’s funding is derived from the Saskatchewan Ministry of Social Services, 13% from the Saskatchewan Ministry of the Economy, and 4% from the Government of Canada, meaning that approximately 50% of revenue for Inclusion Saskatchewan is derived from public funds⁵⁰⁵, and this speaks to the recognised legitimacy of the organisation. Inclusion

⁴⁹⁹ SAMR.

⁵⁰⁰ McTavish, “Interview Notes.”

⁵⁰¹ McTavish.

⁵⁰² McTavish.

⁵⁰³ McTavish.

⁵⁰⁴ McTavish.

⁵⁰⁵ SACL, “Annual Report 15/16.”

Saskatchewan receives other funding from sources such as the Saskatchewan Institute on Community Living (SICL), which is a clothing recycling program partnered with Value Village (Savers, Inc), the Saskatchewan Lotteries Trust Fund, and through Inclusion Saskatchewan's direct fund raising efforts.⁵⁰⁶ At the same time, Inclusion Saskatchewan applies 59% of their budget toward direct supports for the individuals and families they advocate for.⁵⁰⁷ An additional 11% is spent on researching and promoting Inclusion Saskatchewan's strategic initiatives, which focus on improving public policy on such things as inclusive education, the Saskatchewan Assured Income for Disability (SAID), and Self-Directed Funding (SDF).⁵⁰⁸ The scale of the organisation's operations demonstrate that Inclusion Saskatchewan has significantly expanded their mission since the earliest days when the association consisted of a small group of determined parents who were seeking better education opportunities for their children.

The Rise of a Social Movement:

It all began with a young girl named Norma. Soon after two-year-old Norma was adopted by Dr John Dolan and his wife, it became apparent that she was experiencing developmental delays.⁵⁰⁹ Although the Dolans were offered options, they insisted on keeping and raising Norma. Dr Dolan described the response from social services as: "[t]he welfare people said they were sorry the little girl wasn't right, and they were going to take her back. We decided they weren't going to take her away. If any little girl needed a mother and a dad, that one did".⁵¹⁰ To assist Norma, and many other children, Dr Dolan went on to create the organisation that would eventually become Inclusion Saskatchewan⁵¹¹. Within a few years, the

⁵⁰⁶ SACL.

⁵⁰⁷ Inclusion Saskatchewan, "Annual Report 2018/2019" (Saskatoon, 2019).

⁵⁰⁸ Inclusion Saskatchewan.

⁵⁰⁹ Sheila Junor, "Dr John Dolan Retires," *Dialect* (Saskatoon, September 1981).

⁵¹⁰ Junor.

⁵¹¹ Travis Neufeld, "60 Years in the Making," *Dialect* (Saskatoon, 2016).

organisation partnered with other provincial organisations to form the Canadian Association for Community Living (CACL), which was founded in 1958⁵¹². Today, CACL recognises the early Saskatchewan social movement for inclusion, along with other early movements that existed in Ontario and Montreal, as the grassroots organising effort that led to the formation of their national organisation⁵¹³.

Dr Dolan took his role as Norma's father very seriously. After learning that his new daughter had an intellectual disability, Dr Dolan immersed himself in the existing literature on the topic.⁵¹⁴ Realising that other parents needed information about their children's conditions, Dr Dolan began to disseminate what he was learning, and he provided families with information about their child's condition and the resources that were available for them.⁵¹⁵ As well, in 1957, Dr Dolan organised the first Saskatchewan seminar about intellectual disability.⁵¹⁶ After serving as president of the organisation for some years, Dr Dolan additionally served as the executive director of SAMR between 1969 until his retirement in 1981.⁵¹⁷ Dr Dolan used his self-taught knowledge in service to various boards, such as for Elmwood Residence Ltd, Cosmopolitan Industries Ltd, the Saskatoon Convalescent Home, the Government of Saskatchewan Institution Visiting Committee, the Alvin Buckwold Centre, the Mental Retardation Advisory Board to Core Services, the Advisory Board for Saskatchewan Association for Rehabilitation Centres, and many other organisations.⁵¹⁸ Dr Dolan's commitment to learning about intellectual disability, and his work promoting the ideals of inclusion and helping to ensure that persons experiencing

⁵¹² Neufeld.

⁵¹³ Canadian Association for Community Living, "About Us," CACL.ca, 2019, <https://cacl.ca/who-we-are/about-us/>.

⁵¹⁴ Junor, "Dr John Dolan Retires."

⁵¹⁵ June Avivi, "Interview Notes" (Saskatoon, 2015).

⁵¹⁶ Junor, "Dr John Dolan Retires."

⁵¹⁷ Junor.

⁵¹⁸ Junor.

intellectual disability were receiving appropriate education and care eventually earned him an honorary Doctor of Laws Degree from the University of Saskatchewan's College of Education in 1977.⁵¹⁹

Achievement through Collective Effort:

Although Dr John Dolan's work is recognised as the driving force behind the early goals of the organisation, Dolan did not achieve his success alone. Many different individuals, far too many to describe here, were instrumental in advancing Saskatchewan's social movement for inclusion. The work of the organisation used collaborative methods and continues to use collaborative methods to this day. There is no doubt that various individuals in the social movement for inclusion have been inspired by Dr Dolan's style of leadership, and they have modelled their advocacy after Dolan's example. A main feature of Dr Dolan's advocacy was the ability to work co-operatively with other advocates, and to work collaboratively with the appropriate government ministries and service organisations to find a beneficial outcome to the problems at hand.

From the earliest beginnings of the social movement for inclusion, education was at the top of the agenda. In the mid-1950s, when it became time to enrol his daughter in school, Dr Dolan discovered that there were no education programs available for Norma within the community, and he found this situation to be intolerable. During that time period, a child was required to score 70 or better on an IQ test before they were permitted to attend school, even if the child's parents were taxpayers.⁵²⁰ To cope with the situation, Dr Dolan relocated his family from the rural village of Girvin to the city of Saskatoon in the hope that Norma would be able to get an education. As well, Dr Dolan purchased an advertisement in the StarPhoenix newspaper

⁵¹⁹ Junor.

⁵²⁰ McTavish, "Interview Notes."

that was meant to find other parents who had been unable to enrol their children in local day schools. The advertisement was simply worded, stating only:

Attention Parents! A survey is being conducted to find the number of mentally retarded, educatable children in Saskatoon, who are unable to attend any special class at the present time. If you have a child or know of any, contact W.J. Dolan, 207 Ave. H, South. Phone 7498 After Jan. 3, 1955⁵²¹.

Fourteen families responded to Dr Dolan's advertisement and together they founded the organisation that would eventually become Inclusion Saskatchewan.⁵²² During these earliest of days, the organisation consisted of families that met around kitchen tables and in living rooms. Another founding member, June Avivi, describes her experiences with the early organisation as: "[v]ery much a fly-by-night operation at that time. A lot of people put in blood, sweat, and tears. There were a lot of parlour meetings. ...it started out with a tiny office in the Canada Building – it was a closet. Gradually it grew from there".⁵²³

Dr Dolan described the early organisation as a "bugging service" meant to lobby governments and agencies to provide appropriate services for children experiencing intellectual disabilities.⁵²⁴ Specifically, Dr Dolan stated: "[t]he purpose of this council shall be to promote the welfare and education of all mentally retarded persons in the community and elsewhere, and to further such programs as may lessen the incidence of this condition".⁵²⁵ Throughout Dolan's tenure as a leader in Saskatchewan's social movement for inclusion, and in his roles as President and executive director of SARC, the organisation kept to this mission.

⁵²¹ Neufeld, "60 Years in the Making."

⁵²² Neufeld.

⁵²³ Neufeld.

⁵²⁴ Neufeld.

⁵²⁵ Junor, "Dr John Dolan Retires."

It was not long after the early organisation was formed that regional branches sprang up in various communities throughout Saskatchewan, each individually led by parents that sought a place in school for their children. As the work of the organisation progressed, however, the organisation began to be more than the “bugging service” described by Dr Dolan, and the organisation started to establish community infrastructure that would serve their children. For example, in 1958, the organisation created the John Dolan School, which provided a recreational day program for children that were not permitted to attend school due to intellectual disability⁵²⁶.

Today, the John Dolan School continues to serve children’s educational goals and has been absorbed into the Saskatoon public school system. Each student is provided a collaboratively designed ‘Personal Program Plan’ that is equipped to provide for multiple special needs with access to physical therapy, speech language pathology, and occupational therapy.⁵²⁷ Although the John Dolan School originally offered far fewer services than it does today, the establishment of a recreational day program served to demonstrate that education programs were beneficial for children experiencing intellectual disability, and that this special education could be offered within the community, rather than only through institutionalised care at the Saskatchewan Training School, which was quite far away from most families’ homes.

Dr Dolan was relentless in his lobbying for increased support for children who had intellectual disability, and he managed to obtain funding and/or support for his school from the provincial government, the Board of Education, and the Saskatchewan Teacher’s Federation⁵²⁸. This support legitimised the John Dolan School, which in turn led to an increase in membership

⁵²⁶ Neufeld, “60 Years in the Making.”

⁵²⁷ SPSPD, “John Dolan School: Inspiring Learning,” Saskatoon Public School District.ca, 2019, <https://www.spsd.sk.ca/school/johndolan/Pages/default.aspx>.

⁵²⁸ Neufeld, “60 Years in the Making.”

for the organisation and the development of additional branches of the organisation located throughout Saskatchewan⁵²⁹.

Through the organisation's efforts, publicly funded special education programs were established throughout the Province of Saskatchewan, meaning that children could attend school within their own communities. For example, SARC organised a collaboration between the Ministry of Education and the Kinsmen Club to fund the Kinsmen School for Retarded Children in Estevan, which opened in 1964.⁵³⁰ The total cost for the school was \$19,700.00, with \$9,034.00 of this amount from the Ministry of Education, \$7,166.00 from the Kinsmen Club, and \$3,500 from SARC.⁵³¹ Additionally, The John Dolan School in Saskatoon became the first special education school in Canada to receive public funds through a school board.⁵³² Although SARC had not yet managed to convince the Saskatoon Public School Board to take on operation of the John Dolan School, a special school board was formed that included representation from the public school board, the separate school board, SARC, the Department of Education, and interested citizens.⁵³³ For 1964, the Special Board was able to provide funding in the amount of \$290.00 for each of the 49 students that were enrolled in the John Dolan School.⁵³⁴ As an organisation that was barely a decade old, SARC appeared to have made great strides toward their main goal, which was to achieve access to education for children experiencing intellectual disability.

⁵²⁹ Neufeld.

⁵³⁰ SARC, "Kinsmen School Opened in Estevan."

⁵³¹ SARC.

⁵³² SARC, "PSB Urged to Operate John Dolan School," *Outlook: Newsletter for the Saskatchewan Association of Retarded Children* (Saskatoon, July 1964).

⁵³³ SARC.

⁵³⁴ SARC.

Special education programs required special teachers and no other person may represent the role of the special education teacher more than Mary Vinish. She began as a teacher at the John Dolan School, and later served as principal for 30 years.⁵³⁵ When Ms Vinish was first hired, she lacked experience in teaching children with disabilities, but she soon embraced the value of inclusion and upgraded her skills to include courses in teaching special education⁵³⁶. During the early days of the organisation, there were very few teachers that had received education in teaching children experiencing intellectual disability, but SARC and SAMR provided many bursaries that allowed interested teachers to upgrade their special education skills. In 1975, for example, SAMR provided 19 bursaries for teachers to take courses in special education, and this was significant as SAMR was the only organisation at that time to offer funding to students pursuing knowledge in special education.⁵³⁷ Ms Vinish, and many other Saskatchewan teachers, improved education for children that have intellectual disability by ensuring that they were aware of and could utilise the best teaching methods known. Gaining expertise in methods of special education can be considered revolutionary during a time when public school boards were unwilling to provide any special education at all, and Ms Vinish was at the forefront of that revolution.

Mary Vinish was very much aware of how difficult it could be to obtain funding for special education projects. Her husband, Dick Baxter, happened to be the Government of Saskatchewan's Director of Services for the Mentally Handicapped, as that position was then known as.⁵³⁸ Mr Baxter would act as the liaison between the Treasury and SAMR, and Mary

⁵³⁵ Neufeld, "60 Years in the Making."

⁵³⁶ Neufeld.

⁵³⁷ SAMR, "SAMR Bursaries Worth \$2000," *Dialogue: Newsletter of the Saskatchewan Association for the Mentally Retarded*, June 1975.

⁵³⁸ Neufeld, "60 Years in the Making."

Vinish recalls her husband's stories about his experiences at meetings between the Treasury and Dolan:

Dick said that when the treasury saw John Dolan and Al Anderson (former SACL Executive Director) coming, they would start quaking in their boots. They (the organisation) had to pound on desks and not go home until they got what they wanted. They had to be strong back then⁵³⁹.

Although Mary Vinish retired from her role as Principal of the John Dolan School in 1986, she continued to work for the values of inclusion by volunteering as a board member at Saskatoon's Elmwood lodge, and also for Cosmopolitan Industries⁵⁴⁰, which is a Saskatoon organisation that promotes opportunity and support for adults who have intellectual disability.⁵⁴¹ To honour Mary Vinish and her contribution to the goals of inclusion, the John Dolan School has named their Snoezelen Park for her, which is a multi-sensory environment that promotes relaxation, cooperation, and participation at sensory-based stations that are based on the Snoezelen philosophy⁵⁴². Mary Vinish's commitment to inclusion and the provision of accessible education for all children has had a lasting impact in Saskatchewan.

Passionate Advocates Create Change:

Although Dr Dolan is recognised as the founder of Inclusion Saskatchewan, and he is a personality that is perennially present within the ideals of the Saskatchewan movement for inclusion of people that have intellectual disability, there are various other inclusion advocates that have made a lasting impact. These inclusion advocates tend to share Dr Dolan's passion to improve social conditions for people who have intellectual disability, and they have been resolved to create the desired change. There were four such advocates associated with Inclusion

⁵³⁹ Neufeld.

⁵⁴⁰ Neufeld.

⁵⁴¹ Cosmo, "Cosmopolitan Industries," cosmoindustries.com, 2019, <https://www.cosmoindustries.com/>.

⁵⁴² SPSP, "John Dolan School: Inspiring Learning."

Saskatchewan that served on the Valley View Centre Transition Steering Committee, and it is generally believed by the stakeholders that this particular combination of inclusion advocates bolstered the success of the Valley View Centre closure project. One inclusion advocate suggested that: “[i]t was the right Minister with the right group of people at the right time. The stars had aligned”. These inclusion advocates were June Aviv, Doug Conn, Gloria Mahussier, and Kevin McTavish.

A bastion of Saskatchewan’s social movement for inclusion was June Avivi, and she has been described by Inclusion Saskatchewan as one of the organisation’s: “[m]ost enduring stewards”.⁵⁴³ Ms Avivi first became aware of the issues surrounding inclusion after her parents sought advice from Dr Dolan⁵⁴⁴. When they were children, June’s brother contracted encephalitis, an inflammation of the brain that often leads to intellectual disability⁵⁴⁵. There were extremely few options available for her brother to attend school, but eventually a local Roman Catholic school agreed to educate both him and the young June⁵⁴⁶.

At first, June was dismayed by the prospect of being educated in a Roman Catholic school, as she and her family practised Judaism, and she worried that she would be pressured to convert to Roman Catholicism.⁵⁴⁷ Recognising the precocious and intelligent young person that June was, the Roman Catholic Sister in charge of the school assured her that when the Roman Catholic students were to participate in religious instruction and ritual, June would be able to spend this time in the library to pursue her own interests.⁵⁴⁸ This plan, which could be described as an act of inclusion, satisfied the young June. Not only would June and her brother be able to

⁵⁴³ Neufeld, “60 Years in the Making.”

⁵⁴⁴ Neufeld.

⁵⁴⁵ Aviv, “Interview Notes.”

⁵⁴⁶ Avivi.

⁵⁴⁷ Avivi.

⁵⁴⁸ Avivi.

attend school together, but young June would be close by to lend a watchful eye over her beloved brother, all without comprising her values and personal needs.⁵⁴⁹

Later in 1956, after she grew up and married, June Avivi gave birth to a son who had intellectual disability. This event brought her back in contact with Dr Dolan, and she began to take on an active role in the organisation, which has led to her recognition as a founding member of Inclusion Saskatchewan.⁵⁵⁰ Her expertise and interest in the education of children experiencing disability was expanded when Ms Avivi became a special education schoolteacher.⁵⁵¹ In this capacity, Ms Avivi worked toward inclusion through integrating her students with other classrooms so that the children would be included in activities such as music, sports, and field trips.⁵⁵²

One of the reasons why Ms Avivi's efforts were unique is because she advocated for persons living in the community, as well as for persons that were living in institutional facilities. In addition to her volunteer work with Inclusion Saskatchewan, June Avivi became involved in the welfare of the residents of the Saskatchewan Training Centre/Valley View Centre (STS/VVC). After her son began to live at STS/VVC, June Avivi was naturally motivated to ensure that residents experienced the best quality of life that was possible.⁵⁵³ As part of this work, June Avivi assisted in establishing the VVC Parent's Advisory Committee in 1989, and later served as chair of the Valley View Centre Family Group (VVCFG).⁵⁵⁴ A compassionate woman, Ms Avivi would volunteer to sit with institutionalised palliative care patients who had

⁵⁴⁹ Avivi.

⁵⁵⁰ Gloria Mahussier et al., "Remembering June Avivi: Stories about June's Life from Those in the Inclusion Movement," *Dialect* (Saskatoon, 2018).

⁵⁵¹ Avivi, "Interview Notes."

⁵⁵² Avivi.

⁵⁵³ Avivi.

⁵⁵⁴ Mahussier et al., "Remembering June Avivi: Stories about June's Life from Those in the Inclusion Movement."

intellectual disability. Ms Avivi believed firmly that persons with intellectual disability should be properly cared for at the end of their lives, but she also witnessed that resources were too often lacking to ensure that a person was not alone in their final hours. When remarking about her brother's passing, Ms Avivi was pleased that someone was able to be with him 24 hours per day: "[t]hat was extremely important to me. I think it is important to every parent. I think it is important to every family. To respect, whether it's a parent or a sibling, not just when they are having a party, but when things are not going so great, too".⁵⁵⁵

Ms Avivi spent most of her life as an advocate promoting the values of inclusion and diversity. Not only was she a special education teacher, but she was a Holocaust educator. For 25 years, Ms Avivi organised a seminar for 2000 Saskatchewan students to educate them about the events of the Holocaust.⁵⁵⁶ One of the features of the seminar was that students would learn about the Holocaust directly from an actual Holocaust survivor.⁵⁵⁷ Once there were no longer any living Holocaust survivors remaining in Saskatchewan, the education program would bring Holocaust survivors to Saskatoon from Vancouver, Winnipeg, Toronto, and Montreal.⁵⁵⁸ For her efforts in promoting inclusion and diversity, June Avivi received the Saskatchewan Order of Merit in 2017. Chief Commissioner David Arnot described Ms Avivi's accomplishments at the Saskatchewan Order of Merit Ceremony:

Great leaders and mentors like June Avivi help shine light into the darkest of areas and encourage students to explore, Thanks to her, students in our province have had a chance to study about the Holocaust, engage in courageous conversations, and learn the importance of protecting and respecting the rights of others. Along with being an educator, for the past 55 years Mrs Avivi has also made important contributions as an advocate

⁵⁵⁵ Avivi, "Interview Notes."

⁵⁵⁶ Avivi.

⁵⁵⁷ Avivi.

⁵⁵⁸ Myron Love, "Holocaust Educator To Receive Saskatchewan Order of Merit," *The Canadian Jewish News*, August 6, 2017, <https://www.cjnews.com/news/canada/holocaust-educator-receive-saskatchewan-order-merit>.

for people with disabilities. Whether with Community Living Association Saskatoon Inc., the Valley View Centre (VVC) Family Group in Moose Jaw, the Saskatchewan Association for Community Living or the VVC Transition Steering Committee, Mrs. Avivi's devotion to creating a better quality of life for citizens with disabilities has left a lasting mark in our province.⁵⁵⁹

June Avivi's style of leadership was so respected by the MSS that they sought her participation in the important task of de-institutionalising the Valley View residents after the decision was made to permanently close the VVC in 2012. Their faith in June Avivi was such that when Former Minister of Social Services June Draude was advised to work with June on the VVC transitions, the MSS staff explained to her that "[t]hey believed that if the two 'Junes' were on the same page, Saskatchewan could set a new benchmark for Canada (maybe the world) in finding homes with supports for vulnerable individuals where they would be treated with respect, dignity, and love".⁵⁶⁰ This faith in the two "Junes" evidently paid off for the MSS and each June credits "the other June" for the successful outcome of using stakeholder engagement in managing the VVC transitions.^{561 562} Importantly, these healthy relationships of mutual respect between inclusion advocates and key government figures has helped to advance the interests of Saskatchewan's social movement for inclusion.

After June Avivi passed away in 2018, Saskatchewan's Ministry of Social Services recognised June Avivi's leadership skills and recalls how she was able to transform the

⁵⁵⁹ Saskatchewan Human Rights Commission, "June Avivi Receives Saskatchewan Order of Merit," Saskatchewanhumanrights.ca, 2017, <http://saskatchewanhumanrights.ca/news/june-avivi-receives-saskatchewan-order-of-merit>.

⁵⁶⁰ Mahussier et al., "Remembering June Avivi: Stories about June's Life from Those in the Inclusion Movement."

⁵⁶¹ Mahussier et al.

⁵⁶² Avivi, "Interview Notes."

adversarial methods of the Parent's Advisory Committee to more effective methods of cooperation and participation⁵⁶³. The MSS states:

Annually, the Family Advisory Committee would participate in VVC's strategic planning sessions that helped shape the Centre's programs and activities. June was masterful at hearing all sides of a debate and coming to workable solutions that took the best interests of everyone into consideration. June was a strong believer in doing things right. She was instrumental in establishing the Mission Statement and Guidelines for the Advisory Committee. This included a commitment to receive advice, submissions and recommendations from parents, concerned citizens and organisations regarding the operation of the Centre. As part of this commitment, June promised to report all actions, recommendations and outcomes to the VVC Family Group, VVC administration and Inclusion Saskatchewan. As an advocate for Valley View residents, she also worked very closely with resident's families to ensure their concerns were heard. June quickly became the voice for those who didn't have one⁵⁶⁴.

Closely associated with June Avivi is Doug Conn, who served as the co-chair of the Valley View Centre Family Group (VVCFG) for many years, and then after June Avivi passed away, was the sole chair of the VVCFG until the institutional facility was closed. Mr Conn also served as the Chair of the Valley View Centre Transition Steering Committee. Within these roles, Doug Conn strongly advocated for the rights of the Valley View residents and focused his attentions on ensuring that promises made by the Government of Saskatchewan were kept.

June Avivi described how she and Doug Conn were a good team in working toward the goals of the VVCFG.⁵⁶⁵ Explaining that the VVFG had few resources in terms of finances and staffing, Ms Avivi stated: "[W]e had Doug. Doug brings a great number of skills from the business perspective. His work experiences. He can read unions. He can read people."⁵⁶⁶ Doug Conn did indeed bring many skills to the table. Another committee member agreed that Mr

⁵⁶³ Mahussier et al., "Remembering June Avivi: Stories about June's Life from Those in the Inclusion Movement."

⁵⁶⁴ Mahussier et al.

⁵⁶⁵ Avivi, "Interview Notes."

⁵⁶⁶ Avivi.

Conn was an asset, stating: “Doug’s voice is very valuable because he has a whole different approach to things”.⁵⁶⁷

Doug Conn’s expertise came from both his corporate experience and his involvement in sport. Before retiring, he was a Director of Operations at Sasktel, and described himself as a “[f]ixer”. As well, Mr Conn spent many years coaching hockey, which he believes provided him skill and insight in his approach to the Valley View Centre transitions, stating: “[I]’m trying to look at it from the family’s perspective, from the resident’s perspective, or from the player’s perspective. As a coach I ask what works for the player. ...I am a player’s coach, so it is all about the players. A resident to me is the player”.⁵⁶⁸

Doug Conn became engaged with the social movement for inclusion due to having an uncle that lived at the VVC/STS for most of his adult life. Although his parents occasionally went to visit this uncle, they never brought Mr Conn with them. Later, when he was an adult, Mr Conn chose to meet his uncle, and so he went to VVC to visit him.⁵⁶⁹ Doug Conn states that:

I built a relationship with him and I looked after him for 28 years. My family and I would take him here and there and all over the place. The doctor from the institution saw that I was looking after my uncle and asked me if I would like to join the family group and be willing to come to the meetings. And I said yes. I thought I would be involved with fundraising or whatever. I had no idea about the closure of the institution then, but I went to the meeting.⁵⁷⁰

Doug Conn continued to be involved in the VVCFG after his uncle died in 2009. He did so because due to his experience as a Director of Operations at Sasktel, he recognised many signs that the government was planning to shut the

⁵⁶⁷ The Stakeholders, “Interview Data.”

⁵⁶⁸ Doug Conn, “Doug Conn Interview” (Saskatoon, 2014).

⁵⁶⁹ Conn.

⁵⁷⁰ Conn.

institutional facility down.⁵⁷¹ Fearing what might happen to the vulnerable Valley

View residents, Mr Conn explained that:

Most people, when their family member dies, they walk. they never come back. I have been there since 2009 because these people are my uncle's friends. My uncle died when he was 86 years old. These people are his friends and I am going to make sure that his friends end up in a good spot. So that is why I am here.⁵⁷²

As he is continuing to have relationships with former Valley View residents, Doug Conn will often communicate to the VVCTSC the ideas that former Valley View residents have.⁵⁷³ In this way, Mr Conn ensures that Valley View Resident voices are heard and considered. As well, Mr Conn remains concerned that transitioned Valley View residents and their families will continue to have a support system in case any problems arise.⁵⁷⁴ To that end, Doug Conn has applied significant effort in assisting VVCFG members to understand that Inclusion Saskatchewan can be trusted to support them and their loved one, now that VVC has been closed.⁵⁷⁵

The VVCFG coming to trust Inclusion Saskatchewan is a major accomplishment, and it is through the work of June Avivi and Doug Conn, the former co-chairs of the VVCFG that made this partnership possible. The effects of a partnership between the VVCFG and Inclusion Saskatchewan were greater cooperation between the two organisations and a greater ability to concentrate on the individual needs of institutionalised Valley View residents. This attitude was considered by both parties to be preferable to dwelling on the political disagreements that disrupted the social movement for inclusion during earlier decades.

⁵⁷¹ Conn.

⁵⁷² Conn.

⁵⁷³ Baumann, "Direct Observation Notes."

⁵⁷⁴ Conn, "Doug Conn Interview."

⁵⁷⁵ Conn.

The rift between SACL and the VVCFG was serious. One inclusion advocate stated that: “[p]eople would say things like you are terrible parents to put your son or daughter in an institution”.⁵⁷⁶ When parents of Valley View residents heard this sort of criticism from SACL, they were upset because they cared for their children and when they had sent their children to STS/VVC, they had done so because they had been advised by the medical community that the institutional facility provided the best care available.⁵⁷⁷ Furthermore, as the social movement for de-institutionalisation intensified, so did the criticism of any form of institutional care.

Within some factions of the international movement for de-institutionalisation, advocates have equated institutional care as akin to the atrocities that were committed in Nazi Germany, and a continuation of eugenics policies toward persons who have intellectual disabilities.⁵⁷⁸ In general, the VVCFG rejected this criticism as extreme, stating that the contemporary care at VVC was not associated with Nazi or eugenics policies.⁵⁷⁹ VVCFG co-chairs, June Avivi and Doug Conn especially rejected the idea that contemporary care at VVC was part of any eugenics program, although each of them were fully committed to de-institutionalisation and for the transition of all Valley View residents to the community. When People First, an advocacy group that sometimes offers extreme views of institutionalised care, claimed that VVC was a concentration camp and a prison for people experiencing intellectual disability, Doug Conn stated that: “[m]y Dad was in the second world war and he spent 967 days in a German prisoner of war camp. Some of June’s family were murdered in the Holocaust. They were telling us the VVC was the same as that. That’s not reality”.⁵⁸⁰

⁵⁷⁶ The Stakeholders, “Interview Data.”

⁵⁷⁷ The Stakeholders.

⁵⁷⁸ The Stakeholders.

⁵⁷⁹ The Stakeholders.

⁵⁸⁰ Conn, “Doug Conn Interview.”

In recent years, Inclusion Saskatchewan has embraced a more moderate and cooperative approach toward de-institutionalisation. The adversarial methods of past SACL advocates have been replaced with strategies to work collaboratively with the Government of Saskatchewan, the VVCFG and other inclusion advocates such as People First. Doug Conn describes his satisfaction with the contemporary leadership of Inclusion Saskatchewan by stating: “[K]evin and Gloria have turned the organisation around by yards because they are a good president and a good executive director”.⁵⁸¹ Mr Conn is speaking of executive director Kevin McTavish, and President Gloria Mahussier.

Gloria Mahussier has been president of Inclusion Saskatchewan for many years and has served on the board for decades. She became an inclusion advocate because she was determined that her son should have the same resources and opportunities as her daughter did. When her son started school, he was mistreated and this greatly upset Ms Mahussier who tearfully reported in a 2011 interview that: “[w]hen (her son) was in Kindergarten, the teacher locked him in the closet”.⁵⁸² Conditions continued to be less than ideal for her son as Ms Mahussier states: “[h]is whole school life, we advocated for him to be included. We changed the provincial education act twice. We had two human rights cases because he was being discriminated against. I have been at this since 1992 and it hasn’t changed in our community. They still have segregated classrooms in the basement”.⁵⁸³ Despite the apparent difficulty in promoting inclusive education, and although her son has now finished his schooling, Ms Mahussier has not given up her advocacy for inclusive education and she continues to lead Inclusion Saskatchewan for the

⁵⁸¹ Conn.

⁵⁸² Inclusiveed, *Gloria Maussier, President Saskatchewan Association for Community Living* (Canada, 2011), <https://www.youtube.com/watch?v=rxVJMY7ZeOY>.

⁵⁸³ Inclusive Education Canada, *Gloria Mahussier, President Saskatchewan Association for Community Living* (Canada, 2011), <https://www.youtube.com/watch?v=rxVJMY7ZeOY>.

benefit of all persons who have intellectual disability. Regarding educating children who have intellectual disability, the original and perennial focus of the organisation, Ms Mahussier states:

Inclusive education is more than the education part. Having our children with their peers and just in the school community makes the world better. ...my daughter had the school of choice that she could go to with her peers, with her friends, and my son didn't. ...I think more professionals in the classroom would help. Training the new teachers that are coming out, or the old teachers that have taught for 20 years, about what inclusion is all about. It is a whole philosophy, it really is. ...We have some really dedicated people...who believe in inclusive education, and one by one, hopefully we will change the world.

As the president of SACL, Gloria Mahussier contributed to softening the approach of Inclusion Saskatchewan so that the widening divide between SACL and the VVCFG would be closed. Ms Mahussier recalls that, in the 1980s, SAMR/SACL's chief mandate was to push for the closure of the VVC.⁵⁸⁴ The relationship between SAMR/SACL and VVCFG became increasingly strained and the SAMR/SACL board members were failing to come to a consensus in terms of approach. Gloria Mahussier explains:

What happened is that it split our board. On one side there was the idea that Valley View had to close because those parents did bad things to their kids by putting them in there. Then, on the other side there were just a couple of us, and we were saying no. Those Valley View parents had no choices, and if they were to have the same choices that we have now, they probably wouldn't have put their child in Valley View. I agree the people shouldn't have been put in there, but that was their only choice at the time. You can't condemn those parents for putting their children in Valley View, and when it closes, we can't throw them out on the streets. Most of the presidents before me just wanted to lock the doors and take the people out without any foresight and planning.⁵⁸⁵

Gloria Mahussier believes that it was due to her approach to the VVCFG and the Valley View residents that led to her, in her capacity as the president of SACL, to be asked to participate

⁵⁸⁴ Gloria Mahussier, "Interview Notes" (Prince Albert, 2017).

⁵⁸⁵ Mahussier.

in the Valley View Closure Steering Committee.⁵⁸⁶ Ms Mahussier states that: “[I] always supported VVCFG members when they came to SACL meetings. We became friends. When I became president of SACL, I changed the approach. It wasn’t just lock the doors, get a bus, and take these people out”.⁵⁸⁷

Kevin McTavish has been executive director of the organisation since 2008 and has been instrumental in the task of de-institutionalising and transitioning the Valley View residents to the community. One inclusion advocate has stated that: “[m]uch of the success of the closure of the Valley View Centre can be attributed to the leadership of Kevin McTavish”.⁵⁸⁸ Kevin McTavish and his staff have been able to provide much of the heavy lifting required to achieve the goals of a large grassroots organisation such as Inclusion Saskatchewan. Fully dedicated to the mission of the organisation, Mr McTavish himself describes the changes that he helped bring to the organisation and his approach to solving problems:

Don’t ever think that we are without fault. We are. Years ago, we didn’t operate very professionally. In my opinion we really turned things around, but the trouble is that once the blood is bad it is hard to get back in there. People sometimes believe that if they yell at the Minister long enough, that the government will do what they want. You don’t do it that way. Some of the people at SACL had this attitude that you grab pitchforks and torches and then storm the legislative assembly. You don’t do it like that. What you need to do is sit down together, get everyone on the same page, make a plan, and move forward”.

Under Kevin McTavish’s direction, the organisation has accomplished many goals that have required close collaboration with government ministries and other advocacy organisations. Of great importance is the de-institutionalisation of Valley View residents and the permanent closure of the Valley View Centre institutional facility, which was accomplished through

⁵⁸⁶ Mahussier.

⁵⁸⁷ Mahussier.

⁵⁸⁸ The Stakeholders, “Interview Data.”

collaboration with the VVCFG and the MSS. Another example is how Inclusion Saskatchewan organised Saskatchewan's disability community to found the Saskatchewan Disability Income Support Coalition (DISC) in 2006. DISC is a group of disability advocates, consumers and organisations that worked collaboratively with the Government of Saskatchewan to create a separate income system for people that have a disability and require income assistance.⁵⁸⁹ By 2011, DISC had succeeded in collaborating with the Government of Saskatchewan to develop and implement the Saskatchewan Assured Income for Disability (SAID).

Through Inclusion Saskatchewan's leadership, DISC has continued to act in an advisory and consultative role with the Government of Saskatchewan to accomplish meaningful policy changes. In 2015 SAID benefits were increased by up to \$50.00 per month in 2015, which brought the average SAID benefits to \$1,300.00 per month.⁵⁹⁰ Furthermore, DISC succeeded in changing SAID's earned income exemption rules. Originally, single individuals could earn up to \$325.00 per month before benefits would be clawed back⁵⁹¹. DISC consulted with the Government of Saskatchewan, advising a more functional way to deal with the income exception. By 2018, the Government of Saskatchewan had changed the income exemption to an annual exemption of \$6,000.00, rather than a monthly exemption of \$325.00, which would allow people to work seasonal jobs and spread their income exemption over the entire year.⁵⁹²

In 2016, Inclusion Saskatchewan accomplished a goal that they had been working toward for over a decade, which was Self-Directed Funding (SDF) for people that have intellectual

⁵⁸⁹ DISC, "Saskatchewan Disability Income Support Coalition," Saskdisc.ca, 2019, <https://www.saskdisc.ca/>.

⁵⁹⁰ SACL, "Annual Report 15/16."

⁵⁹¹ Inclusion Saskatchewan, "Annual Report 2018/2019."

⁵⁹² Inclusion Saskatchewan.

disability.⁵⁹³ In discussion of their success, President Gloria Mahussier described Inclusion Saskatchewan's delight that SDF was now an option within Saskatchewan:

As both a parent and the president of the SACL, I've been deeply involved in this decade long project, so I know how many hours went into all the research, meetings, discussions, proposals, and presentations. I have never been more proud of our staff, the board, and our partners in the Saskatchewan government for making SDF a reality. Together we have truly changed lives. We have unlocked choices for many families and individuals in Saskatchewan.⁵⁹⁴

Although Kevin McTavish's commitment to collaboration is recognisable in his administrative work for Inclusion Saskatchewan, he is also recognised as being: "[a] peacemaker".⁵⁹⁵ Whenever there have been difficulties during the collaboration process, Mr McTavish has demonstrated an ability to bring the different sides together⁵⁹⁶. Believing the communication between Inclusion Saskatchewan and the MSS to have been very good, Mr McTavish stated:

Any time there is a problem it is usually a lack of communication. Every now and again something happens where someone says something, we say something, or something happened, but really, it is never intentional. Then we talk about it and we find out what happened and then we would resolve it.⁵⁹⁷

Conclusion:

These four people, June Avivi, Doug Conn, Gloria Mahussier, and Kevin McTavish, each share a passion and desire to achieve social justice for vulnerable persons. Whether their individual focus is on inclusive education, or on community living, or on best care practices for

⁵⁹³ SACL, "Annual Report 16/17" (Saskatoon, 2017), https://issuu.com/thesacl/docs/2016_2017_annual_report.

⁵⁹⁴ SACL.

⁵⁹⁵ The Stakeholders, "Interview Data."

⁵⁹⁶ Baumann, "Direct Observation Notes."

⁵⁹⁷ McTavish, "Interview Notes."

persons who have intellectual disability, their shared focus is on the rights and value of the person they advocate for. Participation in the Valley View Centre Transition Committee was no different. Expressing the sentiment that it is always the welfare of the Valley View resident that keeps their focus, the four inclusion advocates will consistently remark on how this focus enabled their collaboration with the government of Saskatchewan to succeed. Statements such as:

We created 14 recommendations. That is our go to point. whenever someone goes off track we just go back to the person centred plan. It comes back to the individual. If we keep the individual in front of us, then we will never lose our purpose for being there. That is the one central thing; that everyone gets what it means to support that person with an individualised plan. We all understand that. As soon as somebody deviates from that, we bring them back to the 14 recommendations. It works like a reset button.⁵⁹⁸

This statement, in a nutshell, is how the inclusion advocates were able to put away old grievances and collaboratively achieve their goal. By concentrating on the individual needs of the transitioning Valley View residents above all else, the focus was shifted away from the historical harms attributed to past institutionalisation and eugenics policies. Although the harms that former governments and medical practitioners had committed in the past should not be dismissed or forgotten, concentrating on improving the lives of remaining Valley View residents took precedence. As well, the Government of Saskatchewan had already accepted that best practices in care had changed and that de-institutionalisation was ideal. Maintaining focus on the needs of the individual Valley View residents is what allowed the substantive work of de-institutionalisation to take place. Ultimately, the effect of healing relationships and moving forward is that inclusion advocates were able to succeed at getting many of the policy changes they wanted.

⁵⁹⁸ Conn, "Doug Conn Interview."

In moving forward, there was no longer any room for criticism toward any parent of a Valley View resident for experiencing a lack of options to properly care for their child. Instead, these parents and other family members were valuable as partners with the Government of Saskatchewan and Inclusion Saskatchewan in the process of de-institutionalising their loved ones. All VVCTSC members worked diligently to ensure that the family members of Valley View residents understood that their voices were included and valued. Also, moving forward meant allowing the Government of Saskatchewan to make things right after decades of policy drift had allowed unsatisfactory care structures to continue. Institutional care was once valued as the best practice in care for persons who have intellectual disability, but the Government of Saskatchewan, at least regarding the Valley View Centre, is now implementing policy that is contemporarily valued as the best practice in care. Inclusion advocates agree that all Valley View residents and their families will benefit from this change and that the Valley View residents are the most important beneficiaries of the policy changes.

Collaboration amongst diverse groups is challenging, but whenever there was a disagreement between Committee members, the issue was resolved through contemplating and meeting the Valley View resident's specific needs as they were individually required. The intense focus on meeting the needs of the individual Valley View resident additionally soothed the worries of other organisations involved in the social movement for inclusion. For example, People First of Canada, an organisation that expressed a great deal of concern for the welfare of the Valley View residents, eventually indicated their approval of the Committee's process of de-institutionalisation. Although People First of Canada were often at odds with the VVCFG, they acknowledged that Valley View residents were indeed being transitioned into the community in situations that were truly based on best practices in care and the values of inclusion, and that the

VVCTSC was the reason for the successful outcome of the project⁵⁹⁹. Overcoming the strife occurring between People First and the VVCFG were due to the leadership of Inclusion Saskatchewan to ensure all transitions met the values of the social movement for inclusion, while also recognising that families should be partners in the de-institutionalisation process. Overall, Saskatchewan's social movement for inclusion is triumphing in their de-institutionalisation goals, and this victory is due to Inclusion Saskatchewan's tradition of activism through collaboration.

⁵⁹⁹ People First Canada and Canadian Association for Community Living, "Proposed National Plan on Deinstitutionalization Discussion Paper," n.d., <http://www.institutionwatch.ca/>.

Chapter 6

Closing an Institution the “Right Way”

Introduction:

Disability policy is normally oriented toward medically accepted ideas about how to care for people who have disability. In the past, a policy of institutionalisation was promoted by the medical community, however, the institutionalisation of people who have disability is an example of public policy that has evolved into obsolescence. Due to acceptance by the medical community to be a best practice in care, policies of institutionalisation gained wide international support and became the foundation of the public welfare policies of many nations. For this reason, the Province of Saskatchewan chose to adopt a policy of institutionalisation. In hindsight, however, Saskatchewan’s historical policy of institutionalisation is now judged by most people to have been unacceptable.

Care practices and social attitudes change over time, and Saskatchewan’s intention to adhere to the best recognised practices in care is evident by the significant changes to disability policy that have occurred over the last century. For example, Saskatchewan chose to end the practice of institutionalising people who have intellectual disabilities in the Saskatchewan Hospital, an institutional facility that functioned to care for people who have mental illness. This change in policy occurred because this practice had been judged to be harmful to people who have intellectual disability, and it had become the medically recognised best practice to institutionalise the two groups of people separately. To remedy the situation, the Government of Saskatchewan built the ‘state of the art’ Saskatchewan Training School in Moose Jaw to educate and care for people who have intellectual disability. Additionally, disability policy continued to evolve as Saskatchewan made some social supports available within the community, such as

special education and housing. Before these social supports became available in the community, such services had only been available within segregated institutional facilities.

Eventually, Saskatchewan embraced de-institutionalisation for all Saskatchewan people who have intellectual disability, and then increased investment in infrastructure that would allow formerly institutionalised persons to live and thrive within the community. Still, the Government of Saskatchewan's track record of implementing change based on evolving best practices in care did not mean that the road was easy for the inclusion advocates who promote change. On the contrary, inclusion advocates have had to work relentlessly over several decades to encourage the Government of Saskatchewan to first recognise that the medical community had revised best practices in care, and then to convince the Government of Saskatchewan to implement policy change. At best, Saskatchewan's disability policy can be described as a process of slow and incremental change.

By the time the Government of Saskatchewan chose to permanently close the Valley View Centre in Moose Jaw, inclusion advocates felt the decision was long overdue. Most other Canadian institutional facilities that housed and segregated people who had intellectual disabilities had already been closed. Still, the delay in closing the Valley View Centre wasn't that the Government of Saskatchewan wanted to maintain a policy of institutionalisation. Instead, the problem was that closing an institutional facility was a monumental task that would not be easily completed, especially one with residents that had been institutionalised for sometimes as many as 60 years. Moreover, when many Western nations chose to dismantle their welfare state economies, the task proved to be enormous. In de-constructing welfare state economies, the economic reforms that were pursued by various nations often took place incrementally and over decades. Saskatchewan was no different.

Closing an institutional facility such as the Valley View Centre, to be completed ethically, requires an overhaul of local economies and a substantial and sustained investment by government. Importantly, everyone involved in the closure, from the sitting government to the citizen stakeholders, wanted to ensure that the residents of Valley View would be safely and effectively transitioned to life in the community. There are various examples of rapid closures of institutional facilities where the residents are forced into a community without adequate social support, but inclusion advocates in Saskatchewan did not wish for a similar outcome for the Valley View Centre. Thus, for many years before the closure of Valley View Centre was announced, Inclusion Saskatchewan, the prominent advocacy organisation for people that have intellectual disability, consistently petitioned the Government of Saskatchewan to allow inclusion advocates and other stakeholders to be involved with the decision making. Due to the collective efforts of Inclusion Saskatchewan and the Valley View Centre Family Group, the Government of Saskatchewan eventually chose to make use of an appropriate citizen participation model that offered a promise of success.

The decision of the Government of Saskatchewan to embark on a path of authentic stakeholder participation was considered by many to be controversial, risky, and untested. Governments across Canada have made use of stakeholder participation on a variety of projects, but the transitions of the Valley View Residents into the community demanded citizen involvement at the highest levels. This meant the government of Saskatchewan had to collaborate with families and other people directly connected to the residents of the Valley View Centre and rely less on advice from parties that had less of a connection to the Valley View residents. The plan was to close the Valley View Centre the “right way” using a “Made in Saskatchewan” approach as Inclusion Saskatchewan and the Valley View Centre Family Group

did not want any repeat of failed institutional closures that have occurred in the past. Success is not simply the closure of the institutional facility. A successful closure of an institutional facility requires the ethical treatment of the institutionalised residents, as well as ensuring that adequate community resources are in place for the remainder of the lives of the transitioned residents. The gamble of utilising authentic stakeholder participation paid off and the closure of the Valley View Centre proceeded successfully, and without the disastrous problems that have afflicted the closure of many other institutional facilities. In the case of the Valley View Centre, it was the use of a citizen participation model that included an appropriate degree of citizen power that led to success.

The need for Authentic Stakeholder Participation:

For several years before the plans to close the Valley View Centre were finalised, many stakeholders were aware that a closure was inevitable.⁶⁰⁰ Inclusion Saskatchewan and the Valley View Centre Family Group worked together to encourage the Government of Saskatchewan to both close the Valley View Centre, and to ensure that Valley View residents would be safely transitioned into the community. Safe transitions into the community necessitated that the Government of Saskatchewan would invest in community infrastructure that would ensure that individuals would have a home to live in, financial support, the ability to receive any needed medical care, and to be able to participate in social activities that are situated within the community. To this end, Inclusion Saskatchewan and the Valley View Centre Family Group urged the Government of Saskatchewan to understand that their expertise was required to ensure the vulnerable Valley View residents would experience safe transitions. Furthermore, each organisation required each other's experience and knowledge to find success.

⁶⁰⁰ The Stakeholders, "Interview Data."

In 2012, when the Government of Saskatchewan publicly announced their plan to close the Valley View Centre in Moose Jaw, the response was mixed. Different stakeholders held different opinions on the matter, and understandably, some stakeholders were concerned about what the future held in store. Some stakeholders would lose their jobs. Other stakeholders feared that the level of care available would be reduced. Of great concern to all was where the Valley View residents would live and who would care for them. Inclusion Saskatchewan and the Valley View Centre Family Group was successful in helping the Government of Saskatchewan to understand that the welfare of the vulnerable Valley View residents was the principal concern that connected all stakeholders, and that the transitions of the Valley View residents to the community must proceed carefully and that these transitions must succeed. The Government of Saskatchewan listened to the advice provided by Inclusion Saskatchewan and the Valley View Centre Family Group and made the decision to facilitate access to the closure project for appropriate stakeholders. These stakeholders were then included in designing the path of transition from the Valley View Centre into the community.

The decision to include stakeholders in the actual design of policy was considered a risk, but the Government of Saskatchewan has pursued a program of increased public engagement on a wide variety of their agenda items.⁶⁰¹ Of note, the Government of Saskatchewan had made election promises to increase the standard of living and supports available for people, with the intention of: “[m]aking Saskatchewan the best place in Canada to live for persons with disabilities”.⁶⁰² Part of this agenda was the Government of Saskatchewan’s promise to consult

⁶⁰¹ Government of Saskatchewan, “Past Public Engagement,” Saskatchewan.ca, 2019, <https://www.saskatchewan.ca/government/public-consultations/past-consultations>.

⁶⁰² Government of Saskatchewan, “People Before Systems: Transforming the Experience of Disability in Saskatchewan” (Regina, 2015).

with the community in developing a disability strategy for improving programs and services.⁶⁰³ Notably, all recommendations listed within the Disability Strategy combined the work of the Citizens Consultation Team with research concerning recognised best practices.⁶⁰⁴ The Government of Saskatchewan's Disability Strategy and the transition of the Valley View residents into the community are connected in purpose. They are each the result of the Government of Saskatchewan's willingness to utilise citizen participation models in the creation of effective public policy.

Some governments seem unwilling to share power with citizen stakeholders despite the benefits of citizen participation being well documented. As a VVCTSC member has stated: "[i]t takes a special kind of leadership on the part of the government".⁶⁰⁵ Benefits of citizen participation range from the idea that enabling stakeholder consultation limits the marginalisation of those with less decision-making power to increasing public confidence in the decisions that are being made.⁶⁰⁶ Additionally, the participation of stakeholders in policy construction is argued to have the effect of transforming adversarial relationships into trusting relationships as different stakeholders get the opportunity to learn about and come to respect each other's views.⁶⁰⁷ Despite these benefits, many governments are wary of the process and will limit the degree of citizen power they provide to stakeholders. Instead of offering full citizen control as was done in the case of the Valley View Centre, many governments choose

⁶⁰³ Government of Saskatchewan.

⁶⁰⁴ Government of Saskatchewan.

⁶⁰⁵ The Stakeholders, "Interview Data."

⁶⁰⁶ Mark Reed, "Stakeholder Participation for Environmental Management: A Literature Review," *Biological Conservation* 141, no. 10 (2008): 2417–31, <https://www.sciencedirect-com.cyber.usask.ca/science/article/pii/S0006320708002693>.

⁶⁰⁷ Reed.

citizen participation models that resemble token participation that merely functions to placate the stakeholder, or that merely fulfil a requirement to inform the citizenry and request feedback.⁶⁰⁸

While any concerned person or group had the ability to provide input to the policy makers, the VVCTSC itself represented a narrow selection of relevant stakeholders. In Sherry Arnstein's foundational typology of degrees of citizen participation, the case of the Valley View Centre could be placed very near the top of her hierarchy. For example, the top three rungs of Arnstein's eight rung 'Ladder of Citizen Participation' are 'Partnership' (rung 6), 'Delegated Power' (rung 7), and 'Citizen Control' (rung 8).⁶⁰⁹ All citizen participation models below these three rungs are considered by Arnstein to be mere tokenism or non-participation.⁶¹⁰ Following Arnstein's theory, the VVCTSC demonstrated a significant degree of citizen power as it was a partnership between the stakeholders and the Ministry of Social Services where the stakeholders were able to direct a desired outcome.⁶¹¹ As well, the work of the VVCTSC demonstrated a degree of delegated power in that they were able to jointly construct the required new policy, and have this policy adopted by the government.⁶¹² Yet, while the work of the VVCTSC demonstrated a large degree of citizen control, the stakeholders were not representative of all possible groups. In the case of the Valley View Centre, the citizen stakeholders were carefully selected. Much of the reason why certain stakeholders were selected over the others is largely due to the ability of individual stakeholder groups to present themselves in a way that received positive attention from the government.

⁶⁰⁸ Sherry Arnstein, "A Ladder of Citizen Participation," *Journal of the American Institute of Planners* 35, no. 4 (1969): 216-44.

⁶⁰⁹ Arnstein.

⁶¹⁰ Arnstein.

⁶¹¹ Arnstein.

⁶¹² Arnstein.

This experiment in using a citizen participation model featuring a high degree of citizen power was a risk for all stakeholders, but the promoted benefits of such a model came to fruition because it was authentic stakeholder participation. Not only did the relevant Valley View Centre stakeholders come to trust one another, but they were able to collaboratively design a successful transition plan for the Valley View residents. When they were ready to get to the work of the project in earnest, the Ministry of Social Services accepted the offer of two prominent stakeholder groups to become involved in the design of the Valley View Centre closure. These stakeholders were the Valley View Centre Family Group (VVCFG), and Inclusion Saskatchewan (INSK). The selection of these stakeholders as government partners was not random, but instead the stakeholders were specifically chosen due to their abilities and role within the community.

It should not be overlooked that the chosen government partners were also the most likely organisations to oppose any unsatisfactory decisions the Government of Saskatchewan might make. When other provinces have embarked on a closure project, it has often been the families of institutionalised residents and inclusion advocates that have loudly condemned what they believe to be wrong-headed decision making. For example, when the Government of Ontario decided to close their last three institutional facilities for the care of people who have intellectual disability by 2009, families of residents responded with legal actions meant to keep the institutional facilities open.⁶¹³ By offering citizen control to the VVCFG and INSK from the start, the Government of Saskatchewan succeeded in avoiding many of the pitfalls that have derailed other closure projects.

⁶¹³ Frank Matys, "Families Launch Legal Action to Stop Closure of Huronia Regional Centre," *Huntsville Forester*, September 9, 2005, <https://www.muskokaregion.com/news-story/3602422-families-launch-legal-action-to-stop-closure-of-huronia-regional-centre/>.

In recent years, Inclusion Saskatchewan and the Valley View Centre Family Group have demonstrated their ability to act co-operatively with one another, and to collaborate effectively with the government to effect change. For this reason, the Ministry of Social Services felt confident that they could rely on people associated with INSK and the VVCFG to assist in the daunting task of de-institutionalising the Valley View residents. In particular, Inclusion Saskatchewan had demonstrated leadership by bringing diverse groups together, putting aside their grievances, and collectively coming to an agreement regarding the future of the Valley View residents. Thus, when the Government of Saskatchewan chose to rely on the expertise of Inclusion Saskatchewan, they were confident this organisation had already achieved the work of merging the goals of the different groups into a single set of ideals.

While there are various models of citizen participation described in the academic literature, the type utilised in the case of the Valley View Centre transitions resembles an ‘owner model’. This type of citizen participation model values the citizen as the owner of the government that they have elected, and that they are obligated to direct that government’s decision-making.⁶¹⁴ Inclusion Saskatchewan, as an advocacy organisation, has embraced this sense of ownership and has routinely advised the Government of Saskatchewan on the many issues that are important to the individuals and families that INSK advocates for. Together with their VVCTSC partners, INSK routinely demonstrated their interest in ensuring that the transitions were: “[d]one right”⁶¹⁵, and that the Government of Saskatchewan kept their promises. Furthermore, since the citizen stakeholders were the main architects of the policies

⁶¹⁴ Kathe Callahan, “Citizen Participation: Methods and Models,” *International Journal of Public Administration* 30 (2007): 1179–96.

⁶¹⁵ The Stakeholders, “Interview Data.”

that were implemented to complete the transitions, they were doubly motivated to ensure that these policies were properly implemented.

There is evidence that the civil servants became motivated to trust in the collaborative process of the VVCTSC over time. Understandably it can be difficult for civil servants to engage with new styles of creating policy recommendation. Any citizen participation model will involve the mixing of citizen expertise with the knowledge of professional policy experts that have experience in implementing chosen policies. The stakeholders may be confident of what policy should be in place, but the civil servants understand the difficulties encountered in implementing policies. Early incompatibility of ideas became viewed as: “[b]umps in the road”⁶¹⁶ that were eventually resolved. As the work of the VVCTSC progressed, the VVCTSC members, both citizen stakeholders and civil servants alike became increasingly homogeneous in their views and once the principal decisions were made, they applied themselves to their task.⁶¹⁷

A VVCTSC member commented that:

“in the beginning, it seemed like the MSS people thought we would just show up occasionally, have a sandwich, and then go home. They did not anticipate our higher commitment to the process. Sometimes, someone could not get their head around the reality that the government now had partners in the decision making. Sometimes there was heated dialogue and sometimes the government’s people had difficulty accepting that we could oversee decisions. In those early days, we were still in the phase of trying to build trust. As trust developed, attitudes changed. Anyone that had difficulty with the process in the beginning is now doing an exceptional job.”⁶¹⁸

As the project progressed, the VVCFG and the families and friends of the Valley View residents came to appreciate the values of inclusion as they witnessed evidence of positive outcomes resulting from the successful transitions of their loved ones. The genuine collaboration

⁶¹⁶ The Stakeholders.

⁶¹⁷ Baumann, “Direct Observation Notes.”

⁶¹⁸ The Stakeholders, “Interview Data.”

of passionate citizen stakeholders with enthusiastic civil servants ultimately led to the successful closure of the Valley View Centre and to the positive transition experiences of the Valley View residents into the community. Through the process of the transitions, the civil servants became inclusion advocates within their own right as there is overwhelming evidence that the VVCTSC members that represented the Ministry of Social Services truly cared about the people that were being transitioned into the community.⁶¹⁹ Examples of their attitudes were repeatedly demonstrated at VVCTSC meetings where the stakeholders would discuss the needs of each transitioning individual.^{620 621} During these discussions, representatives from INSK, VVCFG, and the MSS would refer to Valley View residents by name, remark about how the resident was feeling, expressed interest in what social activities the resident had been enjoying, and what expectations the resident held concerning their new home.⁶²² For inclusion advocates and civil servants alike, it was clear that all VVCTSC members had developed relationships with many of the Valley View residents, and there was a strong desire to ensure successful transitions.⁶²³

The VVCTSC did not just own the recommendations they made, but they also played an active role in the process. Another recognised citizen participation model that reflects the case of the Valley View Centre is the ‘active’ model. In an active model of citizen participation, the stakeholders construct the actual policy that will be implemented, rather than simply providing their opinion or advice on a course of action.⁶²⁴ In the case of the Valley View Centre, the Government of Saskatchewan empowered the citizen stakeholders to conduct research on what the best examples of community living situations were. For example, the VVCTSC toured

⁶¹⁹ Baumann, “Direct Observation Notes.”

⁶²⁰ Baumann.

⁶²¹ VVCTSC, “Valley View Centre Transition Committee Minutes, 2012” (Regina, 2012-2019).

⁶²² Baumann, “Direct Observation Notes.”

⁶²³ Baumann.

⁶²⁴ Callahan, “Citizen Participation: Methods and Models.”

various types of care delivery across western Canada. The information gathered on these tours was valuable for the VVCTSC members to determine what sort of care options should be made available within Saskatchewan.⁶²⁵ Ultimately, when the VVCTSC presented their choices regarding what type of situation would be best for the transitioning Valley View residents, the Government of Saskatchewan adopted them, thus demonstrating that the citizen stakeholders were actively in control of policy direction.

Again, it was the use of an authentic citizen participation model that allowed the Government of Saskatchewan to close the Valley View Centre without major mishap. If the citizen participants were not satisfied in the direction of the closure, there likely would have been consequences. As it was, when the closure was announced, many of the families of the Valley View residents had a difficult time understanding the decision, and it was necessary to bring conflict resolution people to VVCFG meetings.⁶²⁶ A VVCTSC member indicated: “[w]e had a hostile crowd”.⁶²⁷ Since the group that was most likely to sue the Government of Saskatchewan were represented on the VVCTSC and they had control over policy direction, decisions were made that assured the family members that their needs and concerns had been met. Furthermore, the VVCFG served as Chair of the VVCTSC, which ensured their control within a functioning citizen participation model. As partners with the VVCFG, INSK served to ensure that all policy decisions were in line with the values of the social movements for de-institutionalisation and inclusion. In the end, the Government of Saskatchewan was directed by the expertise of their citizen partners, satisfying most stakeholders that the Valley View Centre was closed the “right way”.

⁶²⁵ VVCTSC, “Valley View Centre Transition Committee Minutes, 2012.”

⁶²⁶ The Stakeholders, “Interview Data.”

⁶²⁷ The Stakeholders.

Engaging Stakeholders that are Fit for Purpose:

In closing the Valley View Centre, the citizen participation model utilised by the Government of Saskatchewan applied a vanguard approach to selecting suitable stakeholders. While the sitting Government of Saskatchewan had been astute enough to determine which of the potential stakeholders were required to obtain success, there were many more stakeholders that required attention. Therefore, the Government of Saskatchewan's adopted citizen participation model offered multiple degrees of citizen power for different stakeholders. Ultimately, a citizen powered stakeholder vanguard formed a partnership with the MSS to establish the VVCTSC, while other less powerful stakeholder groups were included through invitations to advise and provide feedback to the VVCTSC. Based on Arnstein's theory, this lower level of citizen participation contains degrees of tokenism,⁶²⁸ and in the case of the Valley View Centre, the input of the less powerful stakeholder groups conformed to this notion. Specifically, Arnstein determined that lower levels of citizen participation concerned placating the stakeholders, consulting with the stakeholders to obtain their ideas and feedback, and the act of informing stakeholders about the events that were to take place. While this type of citizen participation is of use, the stakeholders hold minimal power. In the case of the Valley View Centre, it was only the stakeholder vanguard that held significant decision making power.

Utilising multiple levels of citizen engagement in a single project is highly functional. Multiple stakeholders emerge whenever there are plans to close an institutional facility, but it must be acknowledged that not all potential stakeholders carry the same weight in interest. When the closure of the Valley View Centre was announced, several stakeholder groups came forward to indicate their desire to participate in decision making. Amongst the list of

⁶²⁸ Arnstein, "A Ladder of Citizen Participation."

Stakeholders with an interest in the Valley View Centre were the Saskatchewan Ministry of Social Services (MSS), the Valley View Centre Family Group (VVCFG); the Saskatchewan Association for Community Living (SACL), which is currently known as Inclusion Saskatchewan (INSK); The Canadian Association for Community Living (CACL), which is a national organisation that advocates for people who have intellectual disability; People First of Canada, which is a social advocacy group that promotes the civil rights and de-institutionalisation of persons experiencing intellectual disability; the employees of the Valley View Centre, many of whom were directly involved in the daily care of Valley View residents and had developed bonds of friendship with the residents; the labour union that represented the employees of the Valley View Centre; and the business community as opportunities were opening to expand a full array of community-based healthcare services.

There were various stakeholders beyond those who were directly involved with the Valley View Centre. One of these stakeholders was the City of Moose Jaw as the closure would have economic and social impacts on the immediate region. Even all the citizens of Saskatchewan were stakeholders since they required information and education about what the closure of the Valley View Centre meant for Saskatchewan, and about the benefits of inclusive community living. Any large group of stakeholders will have the potential to conflict with one another, and avoiding unnecessary conflict is a safeguard to project success. Thus, choosing the most relevant stakeholders is thought to be key to success.⁶²⁹ Stakeholders will advance their interests in their decision-making, and there is evidence that including the best stakeholders will improve the quality of outcomes and result in fewer conflicts arising between stakeholder

⁶²⁹ Sam Erevbenagie Usadolo and Marc Caldwell, "A Stakeholder Approach to Community Participation in a Rural Development Project," *Sage Open* 1, no. 9 (2016), <https://journals.sagepub.com/doi/pdf/10.1177/2158244016638132>.

groups.⁶³⁰ Therefore, the selection of appropriate stakeholder partners was likely the most important decision that the Ministry of Social Services made.

Since there were many stakeholders that possessed different degrees of interest, one of the very first tasks of closing the Valley View Centre was to determine which of the identified stakeholders were the best fit for the daunting task that lay ahead. Crucially, the Government of Saskatchewan's preferred Stakeholders were first added to the VVC Joint Planning Committee, and together with the MSS, were given control over which additional stakeholders would become members of the VVCTSC.⁶³¹ In the end, not all stakeholders were invited to the table, and this was due to VVCTSC members' concerns that certain stakeholders might advance their own agenda, rather than remaining focused on the interests of the Valley View residents. For example, the Valley View employees and the union that represented them were stakeholders, but their participation as members of the VVCTSC was thought to be a conflict of interest.⁶³² Therefore, Valley View employees were to participate in the closure as part of working groups, but not as members of the VVCTSC itself.⁶³³

It was further decided that People First would not be represented on the VVCTSC due to the difficult relationship that existed between People First and the VVCFG.⁶³⁴ Feedback from Valley View residents had indicated that People First's participation was undesirable as some of the political statements made by People First were considered extreme by some Valley View residents and their families.⁶³⁵ For example, some Valley View residents had indicated that the tendency of People First members to compare life at the Valley View Centre to living in a Nazi

⁶³⁰ Usadolo and Caldwell.

⁶³¹ VVCJPC, "Valley View Centre Joint Planning Committee Minutes" (Regina, 2012).

⁶³² VVCJPC.

⁶³³ VVCJPC.

⁶³⁴ VVCJPC.

⁶³⁵ VVCJPC.

concentration camp was inaccurate.⁶³⁶ Thus, while People First are widely recognised to be a strong and valuable voice in the social movement for de-institutionalisation, in this particular case, it was determined that the VVCFG had a larger interest in the project than People First had.

Despite the exclusion of certain stakeholders from the VVCTSC, it should not be inferred that these excluded stakeholders were silenced. Instead, it was those stakeholders that had the strongest advocacy role connection to the Valley View residents that were ultimately chosen to serve on the VVCTSC, which were Inclusion Saskatchewan and the Valley View Centre Family Group. People First were enabled to provide input on the closure of the Valley View Centre and to express their ideas and values to the VVCTSC.⁶³⁷ Over the multi-year project, it was clear that the voices of all other stakeholders were respected and attended to as their concerns were frequently discussed at VVCTSC meetings.⁶³⁸ Ultimately, People First expressed their satisfaction with the work performed by the VVCTSC on the “Institution Watch” website where they state:

One of the reasons the Valley View Centre (VVC) transition process has been such a success is largely due to the Valley View Centre Transition Steering Committee (VVC-TSC). Formed early on in the Transition process, the committee is a strategic coalition between government and community. Specifically, the committee is comprised of members from the Valley View Centre Family Group (VVCFG), The Saskatchewan Government’s Ministry of Social Services, and the Saskatchewan Association for Community Living (SACL). Together, they have steadily guided the transition process through discussion, debate, and careful consideration. It is a component of the transition process that we believe is entirely unique to Saskatchewan and has proven to play a critical role in the closure of VVC.⁶³⁹

⁶³⁶ The Stakeholders, “Interview Data.”

⁶³⁷ VVCTSC, “Valley View Centre Transition Committee Minutes, 2012.”

⁶³⁸ VVCTSC, “Valley View Centre Transition Committee Minutes 2016” (Saskatoon, 2016).

⁶³⁹ Laurie Larson and Shane Haddad, “A Message from the Taskforce,” Institution Watch, 2016, <https://cacl.ca/wp-content/uploads/2018/01/FINAL-Institution-Watch-Newsletter-Fall-2016-Online.pdf>.

Already convinced of the necessity to close Valley View Centre, the three vanguard stakeholders were crucial and necessary actors required to perform the closure of the institutional facility and transition of Valley View residents into the community. The MSS, for example, were necessary for several reasons as they were the authorising body, the purse, and were directed by the policies chosen by the democratically elected Government of Saskatchewan. The VVCFG were another necessary component as they were people with direct social ties to the Valley View residents. Members of the VVCFG were the parents, siblings, and other relatives of Valley View residents and they were concerned about the continued welfare of their vulnerable family member. Although all stakeholders were motivated to ensure that Valley View residents would have their needs appropriately met, the members of the VVCFG were additionally motivated to ensure that their family members would be appropriately cared for. Thus, a successful stakeholder engagement necessitated that the VVCFG were included in all stages of transition planning.

INSK was especially fit for purpose as not only are they representative of the social movement for inclusion in Saskatchewan, but they additionally function as the province's main advocate for persons who have intellectual disability. Very importantly, INSK has a history of organising disability advocates, collaboration with the Government of Saskatchewan to create appropriate policy change, and they have rehabilitated broken relationships between sparring disability advocates. The MSS recognised that INSK possessed the stability, academic knowledge and expertise that would allow the Government of Saskatchewan to ensure the closure of the Valley View Centre and the transition of the Valley View residents into the community were conducted with the best interests of the Valley View residents in mind. This recognition of INSK was very important as the VVCFG were trusting that what the government

of Saskatchewan was saying about INSK was warranted. As well, INSK ensured that the Valley View residents were able to participate in decisions regarding their future. Having decreased its role in governing the personal lives of vulnerable persons, the MSS now relies on INSK to provide knowledge about community inclusion, and to advocate for citizens of Saskatchewan that have intellectual disability, both collectively and individually, so that the Government of Saskatchewan may make informed policy decisions.

Success was facilitated by the fact that the vanguard stakeholders were all on the same page. The Joint Planning Committee agreed that the Valley View Centre should close and that all Valley View residents should become members of the community. That was not all, however, as all three stakeholders agreed that each person's transition to the community should be individually tailored to allow for Valley View residents to self-direct their futures as much as they were able. Throughout the project, this ethic was referred to as the 'Person Centred Approach' and adherence to this ethic was the engine that drove the project from conception to completion.

In the case of the Valley View Centre transitions, the work that was performed by the VVCTSC members was achieved through reciprocated respect and the acceptance of each other's viewpoints. It appears that the member's trust for one another arose out of the VVCTSC's work product, and therefore potential instability in the membership had a potential to erode mutually developed trust. This, again, is in line with theories concerning citizen participation that claim stakeholders will develop a sense of ownership over their work, which will have a positive effect on their decision-making.⁶⁴⁰

⁶⁴⁰ Reed, "Stakeholder Participation for Environmental Management: A Literature Review."

Although each stakeholder on the VVCTSC was a representative of either INSK, the VVCFG, or the MSS, they were also individuals. Originally, the VVCTSC had seven members that included Doug Conn, Co-chair of VVCFG and the Transition Steering Committee Chair; June Avivi, Co-chair of VVCFG; Gloria Mahussier, President of INSK; Kevin McTavish, Executive Director of INSK; Bob Wihlidal, Assistant Deputy Minister, Income Assistance and Disability Services for the MSS; Beverly Smith, Executive Director, Community Living Service Delivery for the MSS; and Terry Hardy, Project Lead-VVC Transition Planning, Community Living Service Delivery for the MSS.⁶⁴¹ Over the 7 year period of transitions, the membership of the VVCTSC remained stable, with the only exceptions being that June Avivi passed away near the end of 2018, VVCTSC Chair Doug Conn ‘took a break’ for a short time, but returned after June Avivi’s death to resume his role as representative for the VVCFG, and there were some reassignments/promotions for VVCTSC members that represented the MSS. Bob Wihlidal retired in the Spring of 2018, and although he had been moved to another position a short time earlier, Wihlidal remained engaged with the project and continued to participate in meetings. Beverly Smith was promoted to another position very early in the transition process and was replaced by Bob Martinook who became the principle actor in this role. Therefore, the principal VVCTSC members remained essentially the same throughout the entire process, and this stability also facilitated the successful outcome of their work.

The VVCTSC’s attention to the need for continuity in the principal stakeholders supports theoretical claims regarding stakeholder participation as an avenue for building trust and cooperation between adversarial parties.⁶⁴² One VVCTSC member explained that: “[a]new

⁶⁴¹ The Transition Steering Committee, “Valley View Centre Transition Planning: Recommendations to the Minister of Social Services” (Saskatoon, 2013).

⁶⁴² Reed, “Stakeholder Participation for Environmental Management: A Literature Review.”

person on the VVCTSC could never catch up. Plus, you would have to build the trust with the new person. We need to have the same team leaders all the way to the end”.⁶⁴³ Long before the time of June Avivi’s death and Bob Wihlidal’s retirement, the work of the VVCTSC was functionally complete. All decisions had been made, all agreed upon policies were being implemented, and the transitions were proceeding as planned. By 2016, the VVCTSC members insisted that failure to close Valley View Centre was impossible.⁶⁴⁴

What it takes to Close an Institution: Committing to a Multiple Year Project:

During the multi-year process of creating inclusive community infrastructure and transitioning Valley View residents into the community, it became apparent that a deep commitment to the project was required for it to succeed. Appropriate transitions into the community required the engagement of stakeholders who have personal ties to the Valley View residents, and who would be resilient to the unrealised difficulties that would inevitably arise. To achieve success, all members of the VVCTSC had to be in it for the long haul, and this duty to serve was important for the civil servants as much as it was for the citizen participants. VVCFG co-chairs Doug Conn and June Avivi each had a family member who had resided at Valley View for multiple decades. Gloria Mahussier has been a strong advocate for inclusion for her son and all members of the community, and she has served as President of SACL/INSK for many years. As well, all members of the VVCTSC demonstrate that they have an advanced knowledge about best practices in care for people experiencing intellectual disability, and nearly

⁶⁴³ The Stakeholders, “Interview Data.”

⁶⁴⁴ The Stakeholders.

all members of the VVCTSC speak regularly of the relationships they have with Valley View residents or other people experiencing intellectual disability.⁶⁴⁵

A project in the magnitude of the closure of the Valley View Centre and the transition of all residents into the community obligated the VVCTSC to commit to best care practices; demonstrate a willingness to collaborate with other stakeholders and to listen to the advice these stakeholders provided; and very importantly, to possess an ability to compassionately empathise with the situation of the Valley View residents and their families. Thus, the transitioning of the Valley View residents was not a task for just any old team of bureaucrats. Instead, the best candidates were those who viewed their role as their vocation, and not just another job. Part of the success of the Valley View Centre transition is due to dedicated civil servants who understood the importance of the project and demonstrated interest in a successful outcome. A common phrase uttered by individual members of the VVCTSC was: “[t]his is the most important thing I have ever done”.⁶⁴⁶ Alternatively, individual members would state: “[t]his is the most rewarding work I have done”.⁶⁴⁷ Such phrases indicate that individual members of the VVCTSC were respectful of the significance their involvement in the project had.

When the Valley View Centre Transition Committee (VVCTSC) began the work of the closure, it was unclear how long the process would take. During the early days of planning, the VVCTSC had not yet devised formal policies for the transitions. Neither did the VVCTSC have a funding budget approved, and they would not have any funding approved before VVCTSC was expected to present their strategy to Cabinet.^{648 649} Without funding, the MSS was not even in a

⁶⁴⁵ Baumann, “Direct Observation Notes.”

⁶⁴⁶ The Stakeholders, “Interview Data”; Baumann, “Direct Observation Notes.”

⁶⁴⁷ The Stakeholders, “Interview Data.”

⁶⁴⁸ VVCJPC, “Valley View Centre Joint Planning Committee Minutes.”

⁶⁴⁹ The document cited here was provided to the author on a confidential basis, and are not made available for public view in order to safe-guard the privacy of Valley View Residents.

position to transition any residents during the 2012 fiscal year.⁶⁵⁰ This timeframe was acceptable to the VVCTSC, as it showed the citizen stakeholders that the Government of Saskatchewan was serious about including stakeholder expertise and wishes.

It was very important to the VVCTSC that the process of the Valley View transition be ‘Saskatchewan made’, meaning that stakeholders with ties to the Province of Saskatchewan were able to assert their voices to the project.⁶⁵¹ This ‘Made in Saskatchewan Approach’ included enabling the stakeholders to communicate their values and expertise regarding what a proper transition to community should entail, and the stakeholder engagement had the effect of creating trusting relationships between the VVCTSC members. Mutual trust assured all VVCTSC members that the project was geared toward ‘closing an institution the right way’.

The close attention to detail by the VVCTSC, and their commitment to ‘do things right’ is what led to the project taking seven years to complete. The VVCTSC made it a priority that every Valley View resident would be transitioned to the right community, at the right time, with the best possible community supports. While the project took nearly twice as long as had been originally anticipated, the VVCTSC members understood the extended timeframe as a function of proper planning and attention to the person-centred plan of each individual.⁶⁵² Creating adequate community living infrastructure does not just require a financial investment, but also it takes an investment of time and long term planning. There were occasions when the VVCTSC faced criticism or pressure from other inclusion advocates who worried the de-institutionalisation process was taking too long, but eventually it became clear to most stakeholders that the process was working.⁶⁵³

⁶⁵⁰ VVCJPC, “Valley View Centre Joint Planning Committee Minutes.”

⁶⁵¹ VVCJPC.

⁶⁵² Baumann, “Direct Observation Notes.”

⁶⁵³ Baumann.

Initially, outside observers suspected the VVCTSC was accomplishing very little as years passed with very few transitions occurring.⁶⁵⁴ This appearance of no progress was an illusion, however, as the VVCTSC was deeply engaged in decision making and planning. Once decisions and plans were set, and the relevant infrastructure was built, transitions began to rapidly progress, and continued to progress until every remaining Valley View resident had successfully transitioned to the community.⁶⁵⁵

The VVCTSC began the process of the transitions without a template, and they recognised their task as a difficult one. A VVCTSC member described their activity and attitude toward their task:

We started to work. Our initial task was -- it was huge. It was like a huge cloud and we didn't know what we should tackle first. We knew that the end result had to include a safety net because as soon as parents heard about this there would be hell to pay. It also had to be personalised. There were 200 people and they each had to eat and sleep. Their individual needs had to be recognised. It had to be a specialised program. What are the steps? What are the increments that we are going to have to use? We knew what some of the goals we wanted were, but how do we put this whole mess together? What kind of recommendations can we draw up so that we are consistent and accountable? We are dealing with public money and public perceptions, and so it was extremely challenging.⁶⁵⁶

The task of the VVCTSC was, indeed, “huge”. The VVCTSC had been given the mandate to:

1. Develop transition plans to determine the services required to meet each person's unique needs.
2. Align Saskatchewan with the best practices in service provision for the residents of VVC.
3. Develop services that better support the inclusion of people with disabilities in our communities.
4. Enhance the array of services available to Saskatchewan people.
5. Transition the residents of VVC into new services.

⁶⁵⁴ Baumann.

⁶⁵⁵ Baumann.

⁶⁵⁶ The Stakeholders, “Interview Data.”

6. Discontinue the use of VVC.⁶⁵⁷

These tasks, which had the potential to overwhelm even the most seasoned team of bureaucrats, were to be overseen by a small group of volunteer stakeholders. The bold plan might have appeared risky to many, but then Minister of Social Services June Draude was confident in the method. A VVCTSC member described both the rewards and the risks that came with stakeholder collaboration:

There are always some struggles in the beginning, but this model is going to be copied by education, and by health, and they are going to start bringing in their consumers into the planning and start talking to one another. I am confident that five or ten years from now, I will be able to look and say June Draude left the legacy of how to do this kind of planning. How to bring people from different kinds of backgrounds, but with common goals, and give them the time, and give them the structure within which they can create new ways of doing things. We are being watched, we know that, because people didn't believe that it could be done. They didn't believe the government, parents, and the advocacy people could sit at the same table and work through our concerns to develop a process that is working. I am not saying it was stress-free. That would be a lie.⁶⁵⁸

While it was hard work, the Government of Saskatchewan, parents, and the advocacy people indeed sat together to develop a functional process to complete their tasks. During the meetings, each of the stakeholder groups would provide an update on their progress and inform the others of emerging issues. The VVCTSC members would then assist each other with troubleshooting problems and ensuring that all VVCTSC members respected the 'person-centred approach'. Apparently, this formula worked as this meeting format continued throughout the

⁶⁵⁷ The Transition Steering Committee, "Valley View Centre Transition Planning: Recommendations to the Minister of Social Services."

⁶⁵⁸ The Stakeholders, "Interview Data."

seven years of the project, until all transitions were complete, and the Valley View Centre was permanently closed.⁶⁵⁹

The VVCTSC members took care to foster the personal relationships between them. One VVCTSC member stated that: “[i]t took well over a year before I felt comfortable saying things around the table. ... We had some hot and heavy discussions”.⁶⁶⁰ In the early stages, the work was stressful for the VVCTSC members. Not only were the tasks demanding, but excepting for the executive director of INSK, the citizen participants were unpaid volunteers with competing obligations. VVCTSC members speak of two events that assisted in relationship building and stress relief. The first was travelling together on fact-finding trips allowed the VVCTSC members to spend time together and bond as a group.⁶⁶¹ The second event was a party that was scheduled shortly after the VVCTSC had submitted their recommendations to the Minister of Social Services.⁶⁶² One VVCTSC member remembered that experience as: “[w]e decided we had to get together just for fun, and we got everyone together and we went to a restaurant in Saskatoon and just let our hair down. We brought the ministry people. That was a real bonding experience”.⁶⁶³ While building a collaborative relationship may have been difficult, the VVCTSC members overcame their differences. For most of the seven year process, the VVCTSC were observed engaging in friendly conversation during meeting breaks and had developed a habit of speaking kindly to and about one another both inside and outside of meetings.⁶⁶⁴

⁶⁵⁹ Direct Observation Notes, 2014-2019, Saskatchewan.

⁶⁶⁰ The Stakeholders, “Interview Data.”

⁶⁶¹ The Stakeholders.

⁶⁶² The Stakeholders.

⁶⁶³ The Stakeholders.

⁶⁶⁴ Baumann, “Direct Observation Notes.”

Originally, it was anticipated that the transitions would take approximately four years to complete, which would allow for a permanent closure of the institutional facility by 2016.⁶⁶⁵ As time progressed, however, it became apparent that the task could not be completed within this initial four year timeframe.⁶⁶⁶ As mentioned, the delay was not due to any lapse in available funding or lack of will to close the institutional facility. Instead, the delay was due to the VVCTSC's commitment to ensuring that appropriate community supports were in place. Bob Martinook, executive director of Community Living Service Delivery for Saskatchewan explained through the Media why the closure date was rescheduled to 2019:

I want to make sure that it's clear that the decision to extend the closure date isn't about finance. When the initial closure announcement was made in 2012, there were 207 residents living at the centre. While operating at that capacity, the cost for caring for a resident at centre was less than caring for the same resident if placed in a non-institutional setting. By extending this, it's actually going to cost us more money. We've improved the process. It might have stretched out the time, but it's also been better on people so they know what to expect and how things are happening. We've had 52 very successful transitions, where no one has returned to Valley View and no placement has broken down.⁶⁶⁷

Specifically, Martinook explained that prolonging the amount of time until the ultimate closure of VVC was more costly for the government, and therefore not any sort of cost saving measure. Instead, it was necessary to revise the timeline because each transition was planned individually, and the supports required were based on individual needs. It was necessary to create community living infrastructure through awarding contracts to suitable organisations to build and maintain the new homes in communities across Saskatchewan, to arrange for community based care-providers that could attend to the individualised needs of Valley View

⁶⁶⁵ VVCTSC, "Valley View Centre Transition Committee Minutes, 2012."

⁶⁶⁶ VVCTSC, "Valley View Centre Transition Committee Minutes 2016."

⁶⁶⁷ Brandon Harder, "Moose Jaw's Valley View Centre Closure Pushed Back to December 2019: Extension Will Increase Costs but Benefit Residents, Says Government.," *CBC News*, June 23, 2017.

residents, to ensure that appropriate access to medical care was available after transition, and that transitioned residents would have sufficient options for employment and recreational needs. The installation of community living infrastructure takes a serious commitment of time, planning, and financial commitment to ensure adequate supports exist. No shortcuts were to be taken, even if “doing it the right way” would cost more.

The 14 Recommendations:

By May of 2013, the VVCTSC had succeeded in the collaborative production of a set of recommendations for then Minister of Social Services, June Draude.⁶⁶⁸ The VVCTSC was very firm that their recommendations would ensure that: “[i]ndividuals who currently live in VVC will receive supports equal to or that exceed the support they are currently receiving. ...and that the recommendations will give individuals greater choice in their lives”.⁶⁶⁹ The report states:

A great deal of preliminary work has been completed in the last year, most of which is usually done by government with the individuals and families in private, prior to announcing something as bold as a closure. In choosing to work in a unique and collaborative manner there has been an opportunity to create a meaningful and collaborative process, and to develop a ‘Made in Saskatchewan’ approach. As a result, it may appear as though planning is moving slowly, but the intention is to do it properly rather than quickly.⁶⁷⁰

The result of the VVCTSC’s work became known as ‘The 14 Recommendations’, and once accepted by Cabinet, these recommendations became the instruction manual for the closure of the Valley View Centre and the transition of remaining Valley View residents into the community. The recommendations were:

1. Transition Valley View Centre Services to Community-Based Services;
2. Provide the residents of VVC with the opportunity to live in ordinary homes, in regular neighbourhoods, and in the community of their choice;

⁶⁶⁸ The Transition Steering Committee, “Valley View Centre Transition Planning: Recommendations to the Minister of Social Services.”

⁶⁶⁹ The Transition Steering Committee.

⁶⁷⁰ The Transition Steering Committee.

3. Ensure each VVC resident has a person-centred transition plan;
4. Expand the range of residential services and funding options available creating innovation in service delivery;
5. Ensure there is continuity of services for VVC residents;
6. Facilitate the continuation and development of natural relationships;
7. Ensure VVC residents continue to have access to ancillary services;
8. Expand and enhance crisis prevention and support service capacity;
9. Expand respite services;
10. Ensure each resident has access to individualised activities of choice;
11. Ensure funding is available to support individuals through transition;
12. Develop an Action Plan to implement these recommendations;
13. Develop an evaluation framework;
14. Increase public awareness regarding community inclusion.⁶⁷¹

The 14 recommendations were not hierarchical, and each carried the same weight. The report did outline, however, that these recommendations were necessary to ensure that Valley View residents and their families would be supported through the transition process.⁶⁷²

Ultimately, it was the construction of the recommendations, and their adoption by Cabinet, that ensured the Valley View Centre closure project would reach its successful conclusion. Keeping in mind that the definition of success relied on the personal outcomes of each of the Valley View residents and not simply on whether the institutional facility could have its doors permanently shut. If the Government of Saskatchewan had failed to trust in the work product of the VVCTSC, the citizen participants may have turned against them, but the high level of citizen control, however, ensured that the project would proceed in a manner that was not just acceptable to the stakeholders, but that was designed by the stakeholders themselves.

Rejection of the VVCTSC recommendations would mean rejection of both the values of inclusion and of recognised best practices in care, which would have the effect of derailing the project before it even managed to get started. One VVCTSC recalled: “[w]e never received any

⁶⁷¹ VVCTSC, “Valley View Centre Transition Planning Recommendations to the Minister of Social Services” (Saskatoon, 2013).

⁶⁷² VVCTSC.

pushback for the 14 recommendations. Never. Cabinet approved it. This is the strength of this.”⁶⁷³ Another VVCTSC member reported that: “[w]e wrote it together, and everybody has kept the deal. That was the strength. We wrote a document, we put it together, it was sanctioned by the government”.⁶⁷⁴ The Government of Saskatchewan had chosen to adopt the recommendations, and there was no need for the citizen participants to resist their own policy decisions.

The 14 recommendations were each grounded in the principles of inclusion and careful research, and the expertise available from INSK was invaluable to this process. One VVCTSC member indicated that INSK staff member Nich Fraser’s research into housing was extremely helpful.⁶⁷⁵ Another VVCTSC member reported that Nich Fraser and two ministry staff members wrote the recommendations document, and that all VVCTSC members approved of the contents. Describing the process, one VVCTSC member stated:

We were telling the government that this is the way we think it should be. Sometimes interpretation differs and sometimes things are more difficult to deliver. That is why we spent so much time working on this. Nich and the ministry people brought it to the VVCTSC in March, and it was another two months before it was finalised. It went to the INSK board members, the VVCFG consulted with the families. Everybody has read it multiple times. We were very sure that these recommendations were what we needed.⁶⁷⁶

Enabling the VVCTSC to understand the types of community living supports that would be required, the VVCTSC members toured different community living situations throughout Western Canada. The purpose of these tours was for the VVCTSC to personally identify the best practices that had been used in the closure of other institutional facilities, to learn from the

⁶⁷³ The Stakeholders, “Interview Data.”

⁶⁷⁴ The Stakeholders.

⁶⁷⁵ The Stakeholders.

⁶⁷⁶ The Stakeholders.

practical experiences of the stakeholders involved in other institutional facility closures, and to meet with different organisations and individuals that were providing services to people who had transitioned to the community from an institutional facility.⁶⁷⁷ A VVCTSC member remarked: “[w]e saw some beautiful things, but I learned more from the things that I didn’t like, rather from the things that I liked”.⁶⁷⁸

Importantly, the VVCTSC members agreed that they did not approve of certain forms of care, especially any sort of congregate care. In this context, congregate care refers to a setting where individuals receive care in a large institutional style group home. Specifically, the VVCTSC advised against the Eden Alternative, which is an international, non-profit organisation that markets a trademarked system of care for vulnerable persons.⁶⁷⁹ After visiting facilities that had adopted the Eden system, the VVCTSC members determined that this model did not conform to their vision of community living.⁶⁸⁰ First, the large scale of the Eden facilities, with 8 to 10 residents, was too large.⁶⁸¹ Instead, the VVCTSC had a vision of typical community dwellings shared by 3 or 4 people would be preferred, with a maximum of 6 people in any one setting.⁶⁸² Secondly, the Eden Alternative model is inwardly focused, addressing issues of loneliness, helplessness, and boredom through internal community development.⁶⁸³ The values of the social movement for inclusion, however, call for people experiencing intellectual disability to be included as full members of the community, and have their social needs met within the community. The Eden Alternative, due to its focus on meeting needs through internal

⁶⁷⁷ The Transition Steering Committee, “Valley View Centre Transition Planning: Recommendations to the Minister of Social Services.”

⁶⁷⁸ The Stakeholders, “Interview Data.”

⁶⁷⁹ The Eden Alternative, “About the Eden Alternative,” Edenalt.org, 2019, <https://www.edenalt.org/>.

⁶⁸⁰ The Transition Steering Committee, “Valley View Centre Transition Planning: Recommendations to the Minister of Social Services.”

⁶⁸¹ The Transition Steering Committee.

⁶⁸² The Transition Steering Committee.

⁶⁸³ The Eden Alternative, “About the Eden Alternative.”

community development, was believed by the stakeholders to replicate the segregation from the community that is found within traditional institutional facilities. Therefore, the VVCTSC determined that:

The development of facilities specifically to support individuals with complex medical or behavioural support needs was not recommended. They hinder the growth of community capacity to provide the needed supports. Instead, it was recommended to provide supports in community, provide the needed specialisations in community, and to take the opportunity to develop community capacity over time with the specialised knowledge of existing institutional staff.⁶⁸⁴

Therefore, the first two recommendations, that the Valley View residents would receive community-based services, and that they would receive the opportunity to live in ordinary homes situated in the community of their choice was to become foundational to the entire project. In the first recommendation, the development of community-based services would require many steps and various specific conditions to ensure the well-being of the Valley View residents. For example, it was recommended that the Government of Saskatchewan should no longer be directly involved in service delivery, but instead become the funder, regulator and supporter of the service system.⁶⁸⁵ In order to facilitate this service system, it was advised that new agencies be developed to provide for the residential and support needs of the Valley View residents, and that existing agencies should be supported to ensure that they will adequately adapt to the inclusion of Valley View Residents.⁶⁸⁶ This meant that the Government of Saskatchewan was expected to provide training and professional development opportunities to agencies.⁶⁸⁷ The VVCTSC also desired that there would be close monitoring of individuals after transition to the

⁶⁸⁴ The Transition Steering Committee, "Valley View Centre Transition Planning: Recommendations to the Minister of Social Services."

⁶⁸⁵ VVCTSC, "Valley View Centre Transition Planning Recommendations to the Minister of Social Services."

⁶⁸⁶ VVCTSC.

⁶⁸⁷ VVCTSC.

community, so that stakeholders would be confident that the transitioned individual was safe and thriving.⁶⁸⁸ Related to concerns of health and safety were concerns regarding recruitment and retention of service delivery staff. The VVCTSC members desired that the MSS would remain focused on finding solutions to retention and recruitment problems.⁶⁸⁹

For the second recommendation, the new housing and supports were advised to be dispersed across the community, house no more than four individuals, and be indistinguishable from other houses in the neighbourhoods they are situated in.⁶⁹⁰ Due to their commitment to avoid congregate care situations, the VVCTSC members accepted research that determined that a maximum of three or four individuals living in a single home will enhance independence, choice, and inclusion.⁶⁹¹ In order to fulfil these recommendations, the VVCTSC advised that the Government of Saskatchewan expand their investments in developing residential services, and to make use of housing experts from the Saskatchewan Housing Corporation, the Saskatchewan Association of Rehabilitation Centres (SARC), and local housing developers.⁶⁹²

Equally important was that each Valley View resident receive an individual person-centred transition plan. This meant the VVCTSC expected that the Valley View Centre Community Services Unit and the Valley View staff would be given both the resources and the mandate to begin person-centred planning.⁶⁹³ As well, the VVCTSC expected that the existing Community Living Service Delivery policy statement would be followed.⁶⁹⁴ The pre-existing policy for any Valley View residents that chose to leave the institutional facility required that:

⁶⁸⁸ VVCTSC.

⁶⁸⁹ VVCTSC.

⁶⁹⁰ VVCTSC.

⁶⁹¹ VVCTSC.

⁶⁹² VVCTSC.

⁶⁹³ VVCTSC.

⁶⁹⁴ VVCTSC.

- The individual, their family, and their support network, is included in the transition planning;
- Current care staff at VVC will be involved in the ongoing transition planning;
- Advocates are available throughout the transition process;
- Individuals can choose the location of their new homes;
- Supports in the community are available;
- Community based supports are arranged for each transition; and
- Consideration of the Quality of Life outcomes for each person.⁶⁹⁵

Ultimately, the VVCTSC advised that the MSS would need to carefully develop 197 individualised person-centred transition plans.⁶⁹⁶ VVCTSC members were very firm that in closing the VVC, the Government of Saskatchewan could not take any shortcut and rely on some sort of plan of economic efficiency that would supersede the needs of individuals, or that risk pushing Valley View residents into situations that failed to meet their needs and desires. To avoid this outcome, it was advised that specific resource needs of individuals would be identified before there was any consideration of the type of residential structure that would be built. The VVCTSC justified their position by claiming that:

By planning this way first, the necessary supports can be identified and then put in place around the person. In doing this, planning can maximise the personalisation of service delivery for each individual and ensure that they are considered as a whole person rather than solely on support needs.⁶⁹⁷

Although 197 individualised plans would be more expensive than a systems-based method of de-institutionalisation, the Government of Saskatchewan was already in the process of developing disability policy that prioritised individual needs. In their 2015 disability strategy, entitled *People Before Systems: Transforming the Experience of Disability in Saskatchewan*, the Government of Saskatchewan illustrated their commitment to improving disability programs and

⁶⁹⁵ VVCTSC.

⁶⁹⁶ VVCTSC.

⁶⁹⁷ VVCTSC.

services through person-centred planning.⁶⁹⁸ Specifically, the disability strategy recommendations were focused on:

- Putting people before systems;
- Safeguarding rights and safety;
- Increasing economic and social inclusion;
- Building personal and community capacity;
- Creating accessible communities; and
- Becoming an inclusive province.⁶⁹⁹

During the period when the Government of Saskatchewan was developing and reforming their disability policies, the concepts of inclusivity, accessibility and treating people as individuals were integrated into all their disability policies. Thus, the Government of Saskatchewan were obligated to adhere to their own policies, even when faced with higher costs.

Not only was it recommended that each transition was individually planned to meet the needs of each Valley View resident, but the VVCTSC recognised that service delivery and funding options required expansion. Various forms of housing available in the community were identified and these included: independent living without support from CLSD; supported independent living programs (SILP); group living homes; approved private service homes (APSH); and licensed group homes.⁷⁰⁰ As well, it was recommended that additional funding options would be permitted. Usually, CLSD will only fund not-for-profit community-based organisations to provide services to individuals.⁷⁰¹ There are other options, however, such as for-profit service providers and direct funding models. Since the Valley View residents had unique needs, a self-directed funding option was identified as a strategy that would ensure

⁶⁹⁸ Government of Saskatchewan, "People Before Systems: Transforming the Experience of Disability in Saskatchewan."

⁶⁹⁹ Government of Saskatchewan.

⁷⁰⁰ VVCTSC, "Valley View Centre Transition Planning Recommendations to the Minister of Social Services."

⁷⁰¹ VVCTSC.

personalisation and stability of supports.⁷⁰² Importantly, expanding available services also required additional resources be made available for the organisations that provide services. For example, it was believed that service providers would benefit from training and skills development, as well as education and staff support.⁷⁰³

Since many of the Valley View residents had become quite advanced in age, the VVCTSC was adamant that transitioned individuals would be able to age in place. One VVCTSC member remarked that 10 to 15 Valley View residents die each year: “[b]ecause they are reaching the end of their natural lives”.⁷⁰⁴ Therefore, it was recommended that MSS would further investigate the geriatric and other age related needs for people who have intellectual disability and ensure these needs were met for the transitioning Valley View residents and others.⁷⁰⁵

The VVCTSC also suggested that new models of housing would be explored, as this would expand opportunity for people to make choices about their living arrangements. New models of housing might include: roommate supported living where roommates are contracted to assist the individual in return for reduced rent; 24/7 supported independent living; key ring supports, where several individuals live in close proximity to one another and share support staff; 24/7 supported group living homes where individuals live with friends, but have 24 hour support staff; approved private service homes for people with complex medical and behavioural support needs; home sharing, which involves living with family or friends; clustered housing, where individuals live independently, but share resources; unit housing, which are individual suites with access to shared common areas; care related support homes where individuals are in close

⁷⁰² VVCTSC.

⁷⁰³ VVCTSC.

⁷⁰⁴ The Stakeholders, “Interview Data.”

⁷⁰⁵ VVCTSC, “Valley View Centre Transition Planning Recommendations to the Minister of Social Services.”

proximity to ancillary services; and technologically supported homes where individuals are remotely supported.⁷⁰⁶

Anticipating that the Government of Saskatchewan might reduce services available at VVC as individuals were transitioned to the community, the VVCTSC recommended that services would be maintained until all Valley View residents completed their transitions. This included the demand that internal moves from one VVC area to another would be limited, even as the population of residents declined.⁷⁰⁷ The VVCTSC reasoned that minimising instability would help to maintain the well-being of individuals. Therefore, the VVCTSC warned the Government of Saskatchewan that it was necessary to accept that cost per resident would rise, and that inefficiencies arising from dis-economy of scale would have to be borne to ensure the comfort and safety of the Valley View residents.⁷⁰⁸ This recommendation extended even to the situation of duplication of services.⁷⁰⁹ Very importantly, it was recommended that Valley View residents would transition into community-based supports before they moved to their new home.⁷¹⁰ This meant that individuals would become accustomed to participating in the community, but it also ensured that adequate supports existed before the Valley View residents completed their transitions.

An item of great concern to stakeholders was that Valley View residents were able to continue their relationships with their peers, and with any Valley View employees that they had formed relationships with. The Valley View residents had formed various social kinship groups that included both peers and staff members. As well, individual staff members had formed close

⁷⁰⁶ VVCTSC.

⁷⁰⁷ VVCTSC.

⁷⁰⁸ VVCTSC.

⁷⁰⁹ VVCTSC.

⁷¹⁰ VVCTSC.

bonds with Valley View residents, and this was evidenced by the way that Valley View residents were involved in the lives of the staff members even outside of the institutional facility. Many staff members were known to bring Valley View residents home to celebrate holidays or attend other events.⁷¹¹ Not only did the VVCTSC members believe that resident/staff relationships conformed to the values of inclusion and should be celebrated, but they recommended that it was important for both the residents and staff to maintain these relationships after the transitions were complete.

To facilitate the maintenance of relationships, it was advised that Valley View residents would be able to choose housing where they could continue to live with their friends, if they wished, and that they would have opportunities to continue their relationships with staff members.⁷¹² The maintenance of kinship groups and relationships with Valley View staff were recognised by the VVCTSC as being especially beneficial for transitioned Valley View residents who, after their lengthy period of institutionalisation, had few natural supports existing in the community.⁷¹³ Since the Valley View staff were uniquely positioned to understand the support needs of the Valley View residents, the Valley View staff would be given opportunities to participate in the transition process.⁷¹⁴ Still, the VVCTSC stressed the importance of recognising boundaries that should exist within the resident/staff relationships. In order to avoid reproducing the constraining effects of institutionalisation, the VVCTSC insisted that the needs and choices of the individual Valley View residents should take precedence over the opinions of staff members.⁷¹⁵

⁷¹¹ VVCTSC.

⁷¹² VVCTSC.

⁷¹³ VVCTSC.

⁷¹⁴ VVCTSC.

⁷¹⁵ VVCTSC.

As Valley View residents transitioned into the community, it was necessary to increase awareness about how to support citizens who have intellectual disability. The VVCTSC members believed that the outreach capabilities of CLSD should be expanded: “[t]o develop relationships that foster growth and understanding about supporting individuals with intellectual disabilities”⁷¹⁶. Many Valley View residents chose Moose Jaw as the community they would settle in, and therefore, it was crucial that community-based supports and the social attitudes of physicians and other caregivers in Moose Jaw were welcoming.

Transitioned Valley View residents require services such as transportation, home care, access to medical doctors, dentists, physiotherapists, and much more. Since community-based infrastructure in Moose Jaw was deemed inadequate to receive the influx of transitioned Valley View residents, it was recommended that community-based ancillary services would be developed there. Specifically, this meant the provision of a physical structure to house and administer the newly developed ancillary services.⁷¹⁷ It was also recommended that former VVC staff would be retained to offer ancillary services in the community.⁷¹⁸ Moose Jaw, being home to the Valley View Centre, has many residents that have expertise in providing ancillary services to people who have intellectual disability, and there was now an opportunity to transition the expertise of the VVC staff to community-based services.

Community-based healthcare services require bolstering throughout the province, and since many Valley View residents chose locations outside of Moose Jaw to live, those communities also required infrastructure upgrades. It was recommended, therefore, that the Government of Saskatchewan expand CLSD supports across the province.⁷¹⁹ At the same time,

⁷¹⁶ VVCTSC.

⁷¹⁷ VVCTSC.

⁷¹⁸ VVCTSC.

⁷¹⁹ VVCTSC.

the VVCTSC members recognised that the extreme pressures within Saskatchewan's healthcare sector limited the ability to upgrade services in all areas. Compromises were acceptable in certain situations when a Valley View resident chose to live in a remote area, but the VVCTSC indicated that lack of any service should not thwart transition to the community.⁷²⁰ For example, a transitioned Valley View resident had difficulty accessing physiotherapy in his rural community, and the eventual solution was that a physiotherapist was given a small contract to travel to the community to provide services.⁷²¹ The physiotherapist trained the individual's caregiver on how to do the required daily exercises and then returned monthly to monitor progress and provide further training.⁷²² In a province such as Saskatchewan that struggles with providing healthcare access within remote communities, innovative solutions are often necessary.

The Valley View Centre has traditionally served as the safety net that will support people who have intellectual disability that are facing crises. Closing the Valley View Centre, therefore, required the development of an alternative safety net. The VVCTSC members stressed that any person who has an intellectual disability should not be sent to a mental health facility or a criminal justice facility when facing a crisis.⁷²³ Therefore, the VVCTSC recommended that crisis prevention and service support capacity be expanded and enhanced.⁷²⁴ This meant increasing the number of crisis residential spaces, ensuring they are available 24 hours per day,

⁷²⁰ VVCTSC.

⁷²¹ The Stakeholders, "Interview Data."

⁷²² The Stakeholders.

⁷²³ VVCTSC, "Valley View Centre Transition Planning Recommendations to the Minister of Social Services."

⁷²⁴ VVCTSC.

and eliminating barriers to access.⁷²⁵ As well, these crisis residential spaces should be short term only and facilitate the individual's return to their own home after the crisis ends.⁷²⁶

The VVCTSC recommended that, since crisis prevention is considered a best practice, that additional resources be applied to provide training in crisis prevention.⁷²⁷ This would entail offering crisis response in the home, ensuring access to qualified specialists, and creating transitional housing.⁷²⁸ Importantly, crisis prevention includes access to adequate respite services such as holidays for the individuals, or routine breaks for the care provider. Vacation style respite programming was especially encouraged by the VVCTSC.⁷²⁹

People who have intellectual disability are individuals with unique interests, and they should not be prevented from make choices concerning their daily activity. The VVCTSC members warned against the possibility that transitioned Valley View residents would face isolation in the community due to a lack of opportunity for meaningful activity. Thus, the VVCTSC members recommended that transitioned Valley View residents should have access to the activities of their choice.⁷³⁰ This entailed development of community based programs that provide access to employment and recreation.⁷³¹ As well, transitioned Valley View residents were to be enabled to continue in the activities that they enjoy.⁷³² For example, some Valley View residents enjoyed participating in the Valley View choir, and it was recommended that a similar program be developed in the community for those who were interested.⁷³³

⁷²⁵ VVCTSC.

⁷²⁶ VVCTSC, "Valley View Centre Transition Committee Minutes 2016."

⁷²⁷ VVCTSC, "Valley View Centre Transition Planning Recommendations to the Minister of Social Services."

⁷²⁸ VVCTSC.

⁷²⁹ VVCTSC.

⁷³⁰ VVCTSC.

⁷³¹ VVCTSC.

⁷³² VVCTSC.

⁷³³ VVCTSC.

In the same way that the 14 recommendations were collaboratively constructed, the implementation of the recommendations were to be collaborative performed. To enhance the likelihood of successful transitions, the VVCTSC advised the development of an action plan to oversee the VVC closure project. This action plan included maintaining the VVCTSC to supervise the activities of the closure and that an action plan implementation team be formed.⁷³⁴ This implementation team was to be comprised of the MSS, including CLSD management and staff and VVC management and staff; the VVCFG; INSK, and self-advocates from VVC.⁷³⁵ The responsibilities of the implementation team were the:

- Development of new government and non-government community resources;
- Person-centred planning and transition of the residents to new homes;
- Staged downsizing of the centre;
- A human resource strategy;
- A communications strategy.

To ensure that the 14 recommendations were fulfilled, regular progress reports were advised. The VVCTSC monitored progress by meeting regularly to share concerns. In the first year, VVCTSC meetings were held approximately three times per month, excepting for the summer months when only one meeting was held per month.⁷³⁶ As the project progressed, meetings were held monthly. These meetings were formal with a Chair presiding and recorded minutes. Due to stakeholders being situated in different communities across Saskatchewan, meeting locations were alternated, sometimes in Saskatoon where INSK was situated, sometimes in Regina where the MSS was located, and sometimes in Moose Jaw at the institutional facility itself.

⁷³⁴ VVCTSC.

⁷³⁵ VVCTSC.

⁷³⁶ VVCTSC, "Valley View Centre Transition Committee Minutes, 2012."

The VVCTSC anticipated that once the transitions to community were complete, that there was need of ongoing monitoring of the former Valley View residents. Many stakeholders such as the Valley View residents, their families, the Valley View employees, and inclusion advocates desired ongoing planned oversight and monitoring.⁷³⁷ To accomplish this goal, it was advised that INSK would be funded to provide ongoing advocacy for the transitioned Valley View residents. At the same time, it was advised that CLSD would be tasked with the monitoring of the well-being and quality of care being received by the transitioned Valley View residents.⁷³⁸ Furthermore, to ensure that community supports for the transitioned Valley View residents would not disappear, it was advised that the Government of Saskatchewan should be made accountable over the long-term for the transition outcomes, and be responsible for the provision of ongoing status reports.⁷³⁹ Ultimately, the citizen stakeholders hoped to ensure that the vulnerable Valley View residents were not forgotten once the doors of the institutional facility were permanently closed.

Recognising the need to update social attitudes toward people who have intellectual disability, the VVCTSC recommended a public awareness strategy. Whenever governments announce the closure of any institutional facility, there tends to be considerable controversy arising about the merits of institutionalisation versus community living. To ensure that the public fully understood the social and economic benefits of inclusion, the VVCTSC advised that CLSD, INSK and other stakeholders collaboratively design a public education campaign.⁷⁴⁰ The intent of this recommendation was to ensure that information about the value of inclusion would

⁷³⁷ VVCTSC, “Valley View Centre Transition Planning Recommendations to the Minister of Social Services.”

⁷³⁸ VVCTSC.

⁷³⁹ VVCTSC.

⁷⁴⁰ VVCTSC.

have a wide impact, and that communities would be better prepared to receive formerly institutionalised persons.

As far as closures of institutional facilities normally proceed, the VVCTSC had asked for a great deal. It could be legitimately argued that they had asked for everything. There are no other examples of institutional facility closures in Canada that have accepted such a deep commitment to the demands of the citizen stakeholders, and yet, the Government of Saskatchewan chose to accept all the VVCTSC recommendations. VVCTSC members discuss the reason for Cabinet's acceptance of the 14 recommendations as a matter of: "the stars aligning".⁷⁴¹ This is an accurate description as INSK had petitioned the Government of Saskatchewan for decades to take action on the Valley View Centre, but it appears to have been the right Premier, the right Minister of Social Services, the right civil servants, the right leadership in the VVCFG, and the right leadership in Inclusion Saskatchewan to make the project finally come together.

Capital Infrastructure Costs as a Long-Term Investment in the Care of Vulnerable Persons:

Community infrastructure takes years of planning and development and when the Government of Saskatchewan announced the impending closure of the Valley View Centre, few people believed there was enough community-based housing to meet the needs of the Valley View residents. The VVCTSC insisted, however, that housing infrastructure should be created if it did not yet exist. Not only was it advised that housing should be dispersed across the community in typical neighbourhoods, but that each housing situation should have no more than 3 or 4 individuals living within them.⁷⁴² Furthermore, the VVCTSC advised that the new homes

⁷⁴¹ The Stakeholders, "Interview Data."

⁷⁴² VVCTSC, "Valley View Centre Transition Planning Recommendations to the Minister of Social Services."

be indistinguishable from other homes within the same neighbourhood.⁷⁴³ It was additionally suggested that the MSS would find opportunities to create homes in new housing projects that were under development across Saskatchewan.⁷⁴⁴

To support the transition of Valley View residents to the community, the Government of Saskatchewan purchased, renovated or built 36 residential properties⁷⁴⁵. These residential properties were designed to meet the individual needs of Valley View residents and were located within the Saskatchewan community that was chosen by each Valley View resident and their family⁷⁴⁶. Former Valley View residents will age in place, living out the remainder of their lives in their own homes, and when the time comes that the transitioned Valley View residents will no longer have use of their homes, the properties will be absorbed into the MSS housing inventory.⁷⁴⁷

The citizen participants of the VVCTSC have always understood that policy changes have economic foundations, and that the closure of the Valley View Centre was no different. One VVCTSC member stated:

Part of the closure of Valley View is economic. Let's not deny that. It is costing them more to maintain those buildings than it will to maintain these homes once they are established. There will be an economic savings in terms of this, so economics is a part of it. What I appreciate is the humanitarian way that it is being done. It is people first. The side benefit is economic. The side benefit is that the people of Saskatchewan are going to benefit by the process that is being developed, and by access to new venues in the community. So, when the former Valley View residents no longer need the homes that are being built, they will still be used by the community.⁷⁴⁸

⁷⁴³ VVCTSC.

⁷⁴⁴ VVCTSC.

⁷⁴⁵ Government of Saskatchewan, "Valley View Centre Transition," Saskatchewan.ca, 2019, <https://www.saskatchewan.ca/residents/family-and-social-support/people-with-disabilities/valley-view-centre-transition>.

⁷⁴⁶ Direct Observation Notes, 2014-2019, Saskatchewan.

⁷⁴⁷ Direct Observation Notes, 2014-2019, Saskatchewan.

⁷⁴⁸ The Stakeholders, "Interview Data."

The sentiment toward the economic aspect of an institutional closure by the citizen participants of the VVCTSC was quite a bit different than that experienced by citizen stakeholders in other provinces. This is likely because of the trusting relationships that had developed between members of the VVCTSC. During meetings, it became apparent that VVCTSC members representing the MSS embraced the idea that the welfare of the transitioning Valley View residents superseded any economic agenda.⁷⁴⁹ For example, one MSS participant suggested that he found it obscene that a particular outsider stakeholder was arguing that Valley View Centre should remain open in order to avoid damage to the local economy.⁷⁵⁰

To fulfil the demands of the 14 recommendations, the MSS was required to purchase building lots throughout the province. Some chosen communities, however, had insufficient civil infrastructure to support the needs of additional housing.⁷⁵¹ This meant that upgrading community capacity for services such as sewer and electrical were necessary to complete specific housing projects. As always, all housing was required to conform to local building regulations and neighbourhood covenants, and as per the 14 recommendations, must fit seamlessly into the neighbourhood, indistinguishable from other homes. Thus, the provision of community infrastructure was necessarily deep and likely more expensive than the Government of Saskatchewan had first anticipated.

Housing was not the only investment the Government of Saskatchewan was required to make. In order to support recreational activity in the community, the VVCTSC insisted that resources such as transportation were available.⁷⁵² This recommendation was difficult for the

⁷⁴⁹ Baumann, "Direct Observation Notes."

⁷⁵⁰ Baumann.

⁷⁵¹ Baumann.

⁷⁵² VVCTSC, "Valley View Centre Transition Planning Recommendations to the Minister of Social Services."

MSS to fulfil as CLSD did not normally fund transportation and the logistics of public transportation within Saskatchewan are challenging. Especially in Moose Jaw, the community where many Valley View residents chose to make their home, the need for accessible transportation was high. When the MSS consulted with the Mayor of Moose Jaw, however, they were told that Moose Jaw's accessible transportation program was at full capacity.⁷⁵³ At the same time, the Ministry did not have any funding available to purchase vehicles.⁷⁵⁴ Still, the Valley View residents had access to transportation, and it was considered imperative that there would be continued access to transportation after their transitions to the community were complete. Therefore, the issue had to be resolved and VVCSTC placed the development of transportation services onto their action register. As always, there could be no shortcuts or elimination of services due to costs.

Promotion of the ideals of de-institutionalisation and inclusion:

Best practices in care now demand that people experiencing intellectual disability live and receive care services in the community. In 1955, however, the people of Saskatchewan were told that the Saskatchewan Training School represented the most advanced form of care for people who have intellectual disability. By 2012, the people of Saskatchewan were told that institutional care was obsolete. In just a little over 60 years, there had been a complete shift in ideas and the Government of Saskatchewan could no longer justify keeping the Valley View Centre open. Some of the family members of Valley View residents and other members of the community had difficulty in understanding the change in ideas. Many people were still under the impression that institutionalisation remained a viable social policy.

⁷⁵³ Baumann, "Direct Observation Notes."

⁷⁵⁴ Baumann.

In 2012, the typical Valley View resident was approximately 60 years old and had spent most of their life within the institutional facility. On average, Valley View residents had lived in the institution for 40 years, and some had never known any other home. Many of the parents were reaching the end of their natural lives and were relying on the safety-net of the Valley View Centre to keep their child safe. Whether a parent, sibling, niece, nephew or more distant relation, the family members were rightfully concerned about what the future held for their loved ones. The first questions likely to come to mind were “what will happen to my child now that the Valley View Centre is closing?”, and “how will my child be kept safe?” These were reasonable questions and due to their advanced ages, parents were rightfully worried that they may not see their loved ones settled into a new situation, and this caused a great deal of distress.⁷⁵⁵ One VVCTSC member explained the difficulties:

I had calls where people were crying. They would say they were over 80, and their child was 60 and hadn't been home in over 40 years. They were physically unable to handle this. We had several public meetings with the VVCFG, MSS, and INSK. The families attacked us. We were traitors. We were killing their kids. We realised this was a bigger situation than we could handle, so June Draude arranged to bring dispute resolution people from the Department of Justice.⁷⁵⁶

Complicating matters was the spread of misinformation, and the development of baseless rumours. One particularly leggy rumour that gave the VVCTSC trouble was the claim that the MSS planned to relocate the Valley View residents to a wing of the Saskatchewan Hospital North Battleford (SHNB).⁷⁵⁷ This rumour was false, and the new SHNB facility would not even be completed until after the VVC transitions occurred. Furthermore, the rumour was especially disturbing as the SHNB project is a 284-bed psychiatric facility that includes 96 secure beds that

⁷⁵⁵ The Stakeholders, “Interview Data.”

⁷⁵⁶ The Stakeholders.

⁷⁵⁷ VVCTSC, “Valley View Centre Transition Committee Minutes, 2012.”

will serve as a correctional facility for offenders experiencing mental illness.⁷⁵⁸ This new hospital facility was a replacement for the old Saskatchewan Hospital where Tommy Douglas worked and determined that people who have intellectual disability should be cared for separately from people experiencing mental illness.

Trans-institutionalising people who have intellectual disability is contrary to the values of inclusion as it is embraced by inclusion advocates. Although there had been other rumours concerning trans-institutionalising Valley View residents to various other hospital settings, this SHNB rumour was attracting a great deal of negative attention.⁷⁵⁹ Some stakeholders had become mistakenly convinced that Premier Wall had announced the SHNB plan in a speech, and they were demanding answers.⁷⁶⁰ The media had also become aware of the rumour and a Moose Jaw newspaper published a ‘letter to the editor’ that criticised the SHNB plan.⁷⁶¹ Part of the effect of the SHNB rumour, along with all related rumours concerning trans-institutionalisation of Valley View residents to hospitals, was to create confusion for the family members who had been told they would be participating in decision making for their loved ones.⁷⁶² If these rumours were true, the family members were rightfully concerned that decisions had already been made, and that family members would not be able to properly oversee their loved one’s transition. Therefore, these developments made it necessary for the VVCTSC to formally assure family members, Valley View residents, and other stakeholders that such a plan did not exist.

⁷⁵⁸ Government of Saskatchewan, “Saskatchewan Hospital North Battleford Project,” Saskatchewan.ca, 2019, <https://www.saskatchewan.ca/residents/health/new-health-care-facilities/saskatchewan-hospital-north-battleford-project>.

⁷⁵⁹ VVCTSC, “Valley View Centre Transition Committee Minutes, 2012.”

⁷⁶⁰ VVCTSC.

⁷⁶¹ VVCTSC.

⁷⁶² VVCTSC.

To remedy the situation, a VVCTSC member representing the VVCFG explained to the worried stakeholders that no transition decisions had yet been made, and that the goal was to enhance the care of people experiencing intellectual disability.⁷⁶³ As well, Premier Wall responded to the criticism sent to the newspaper with a letter of his own. Although the SHNB rumour was not acknowledged in this letter, the letter gave assurances that all transitioned Valley View residents would enjoy the same quality of life or better, and that the Government of Saskatchewan's plans were to improve the variety of services that were to be available in the community.⁷⁶⁴ As the Valley View residents began to transition into their new homes, these rumours disappeared. Regular transition reports were circulated to the families to assure them that transitions were going well, and these reports included the testimonies of people that were happy in their new home.⁷⁶⁵ These testimonies appear to have influenced the families to become cooperative and involved with their loved one's individual transition plan.⁷⁶⁶

Another major flashpoint concerned the Valley View employee's union. A VVCTSC member stated: "[w]e had to deal with the union who were very upset".⁷⁶⁷ To meet their obligations to the Valley View employees, the Government of Saskatchewan chose to negotiate lay-offs through collective bargaining.⁷⁶⁸ Some positions were eliminated through attrition as employees were nearing retirement, and others were provided with severance packages. Tensions in Moose Jaw were high as the Valley View Centre had served as the second largest employer for many decades. One VVCTSC member stated: "[t]he City of Moose Jaw and its

⁷⁶³ VVCTSC.

⁷⁶⁴ VVCTSC.

⁷⁶⁵ Baumann, "Direct Observation Notes."

⁷⁶⁶ Baumann.

⁷⁶⁷ The Stakeholders, "Interview Data."

⁷⁶⁸ The Stakeholders.

Mayor was upset. Basically, Valley View was one of the prime employers in the community and there was fear about what the closure would do to the economy”.⁷⁶⁹

To mitigate problems arising out of misinformation and lack of understanding about de-institutionalisation and the values of inclusion, a public education campaign was launched. One of the ways that positive information about inclusion was shared with the general public was by running inclusion videos in theatres directly before the movie started.⁷⁷⁰ Another method was to showcase the happiness of former Valley View residents that were thriving in the community. To this end, several former Valley View residents described their new living situations and community activities to the news media.⁷⁷¹ Importantly, there was a unified message from both the Government of Saskatchewan and the inclusion advocates that de-institutionalisation was necessary, and that the entire community would benefit.

How to fail at closing an Institution:

It is possible for governments to not succeed at closing an institutional facility, and failure can be demonstrated to result from a lack of planning, a lack of stakeholder consultation, and from taking shortcuts. Just as touring a variety of community living alternatives had assisted the citizen stakeholders to understand what type of care arrangements they did not like, reviewing failed closures of institutional facilities will provide governments with knowledge of strategies they should avoid. There are many examples where provincial governments have tried to take shortcuts, and their lack of investment has resulted in trans-institutionalisation, the loss of a social safety net for vulnerable persons, and failure to transition

⁷⁶⁹ The Stakeholders.

⁷⁷⁰ Baumann, “Direct Observation Notes.”

⁷⁷¹ Kendall Latimer, “Former Valley View Centre Residents Talk about Life beyond the Institution,” *CBC News*, August 20, 2018, <https://www.cbc.ca/news/canada/saskatchewan/reflecting-valley-view-centre-transition-1.4786473>.

institutionalised residents into the community. As well, failure to include relevant stakeholders in the policy construction process can have the effect of creating adversarial relationships between the government and citizens. A spectacular example is the Michener Centre in Alberta where an attempt was made to transition the Michener Centre residents in an extremely short timeframe. Through analysis of what went wrong in the process of attempting to close the Michener Centre, it is possible to better understand the strengths of the process utilised to close the Valley View Centre.

Originally named the Provincial Training School for Mental Defectives, this institutional facility was opened in 1923, and in accordance with the ideals of Alberta's eugenics program, nearly 3000 training school residents were involuntarily sterilised between 1923 and 1972.⁷⁷² Additionally, training school residents were subjected to experiments concerning the effectiveness of various antipsychotic medications, as well as many other types of medical experiments.⁷⁷³ After the Alberta eugenics program was halted in 1972, the institutional facility was renamed the Michener Centre with the intention of offering residents a more appropriate form of care. At its peak, the institutional facility was considered a 'city unto itself', and even included an operational farm, but admissions sharply declined as community living increasingly became recognised as the best form of care for people who have intellectual disability.⁷⁷⁴ In 2013, the Alberta government announced that the Michener Centre would permanently close.⁷⁷⁵

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⁷⁷² Josh Wingrove, "Aberta's Michener Centre Can't Shake Sordid History," *The Globe and Mail*, March 15, 2013, <https://www.theglobeandmail.com/news/national/albertas-michener-centre-cant-shake-sordid-history/article9848678/>.

⁷⁷³ Leung, "Provincial Training School."

⁷⁷⁴ Baumann, "Direct Observation Notes."

⁷⁷⁵ Wingrove, "Aberta's Michener Centre Can't Shake Sordid History."

⁷⁷⁶ Baumann, "Direct Observation Notes."

A VVCTSC member described the attempted closure of the Michener Centre as: “[a] disaster. Where would the people have gone? It would be round pegs in square holes”.⁷⁷⁷ This statement is in response to the government of Alberta’s decision to close the Michener Centre without first consulting resident’s families, or any other stakeholders.⁷⁷⁸ Additionally, the Government of Alberta directed that the Michener Centre residents were to be transitioned to the community in less than a year, while the resident’s families believed that their vulnerable loved ones had nowhere to go.⁷⁷⁹ ⁷⁸⁰ Staff working on the closure and transitions remarked that there was no appropriate capital plan, and that they had to frantically find and create housing in the community.⁷⁸¹ To facilitate this task, 10 million dollars in contracts were suddenly tendered.⁷⁸² Although approximately 50 people were transitioned to the community, this achievement was in the face of aggressive opposition from stakeholders and the media.⁷⁸³

Immediately after the closure was announced, various Michener Centre stakeholders began to organise in the hope of stopping the closure of the institutional facility. In April of 2013, approximately 250 people comprised of employees, residents, and family members of residents attended a protest rally at the Red Deer city hall, and this event was widely covered by the media.⁷⁸⁴ A wide-spread and troubling narrative emerged concerning the closure of the Michener Centre. This narrative charged that the Government of Alberta was closing the

⁷⁷⁷ The Stakeholders, “Interview Data.”

⁷⁷⁸ Baumann, “Direct Observation Notes.”

⁷⁷⁹ CBC News, “Critics Pan Decision to Close Centre for Disabled Adults: Red Deer’s Michener Centre Home to 125 Developmentally Challenged Clients,” *CBC.Ca*, March 13, 2013, <https://www.cbc.ca/news/canada/calgary/critics-pan-decision-to-close-centre-for-disabled-adults-1.1409452>.

⁷⁸⁰ Baumann, “Direct Observation Notes.”

⁷⁸¹ Marilyn A. Winkleby, “The Stanford Medical Youth Science Program: 18 Years of a Biomedical Program for Low-Income High School Students,” *Academic Medicine*, 2007, <https://doi.org/10.1097/ACM.0b013e31802d8de6>.

⁷⁸² Baumann, “Direct Observation Notes.”

⁷⁸³ Baumann.

⁷⁸⁴ CBC News, “Rally Held in Red Deer for Michener Centre,” *CBC.Ca*, April 10, 2013, <https://www.cbc.ca/news/canada/calgary/rally-held-in-red-deer-for-michener-centre-1.1340445>.

Michener Centre simply to be able to save \$100,000.00 per resident annually, that the government would stand to earn millions by selling the Michener Centre land to developers, and that community situated group homes were unsafe and unable to provide adequate care.⁷⁸⁵

Despite the Alberta Association for Community Living (AACL) attempting to spread information about the merits of de-institutionalisation, the friends and families of the Michener residents asserted that the Michener Centre was not an institution, but rather, that the Michener Centre represented the best available care in the province.⁷⁸⁶ The public outcry to keep Michener Centre open was enormous, with the trustees for the Red Deer Public School Board and the Red Deer city council pressing the provincial government to change its mind.⁷⁸⁷

The public outcry did not abate, and a year later, it was reported widely in the Media that five transitioned individuals had died.⁷⁸⁸ Not only did the advocacy group known as Friends of the Michener Centre call for an investigation and claim that the deaths were directly linked to the transitions,⁷⁸⁹ but one of the non-profit agencies that had been contracted to provide care for three Michener Centre residents had also complained to the media⁷⁹⁰. Executive Director Marie Renaud of the LoSeCa Foundation stated that she could not get any information about the personal needs of the transitioning individuals, and that:

We're going to take out a mortgage, buy a home, retrofit it for a wheelchair. We need some physical information. We need preferences. We need to know what kind of community setting is going to work for these folks. Each resident, many who have lived at Michener for decades, will only be given \$1000.00 when they leave. A thousand dollars to start a new life. You know they've been denied the ability to work or the ability

⁷⁸⁵ CBC News.

⁷⁸⁶ CBC News.

⁷⁸⁷ CBC News.

⁷⁸⁸ CBC News, "Deaths of Former Michener Centre Residents Prompt Calls for Investigation," *CBC.Ca*, August 20, 2014, <https://www.cbc.ca/news/canada/calgary/deaths-of-former-michener-centre-residents-prompt-calls-for-investigation-1.2742441>.

⁷⁸⁹ CBC News.

⁷⁹⁰ CBC News, "Michener Centre Transition Going Poorly Non-Profit Claims," *CBC.Ca*, March 27, 2014, <https://www.cbc.ca/news/canada/edmonton/michener-centre-transition-going-poorly-non-profit-says-1.2589552>.

to earn an income their entire lives because they were institutionalised. And they get a \$1000.00. It doesn't seem right. This transition is just a colossal failure at this point.⁷⁹¹

Such negative media attention and the accompanying public outcry was devastating for the Michener Centre closure project, but the Government of Saskatchewan managed to avoid these problems with the use of stakeholder participation in the decision process. For example, the VVCTSC was committed to ensuring that adequate community supports would be in place before the Valley View residents were transitioned.⁷⁹² Saskatchewan's deep investment in community infrastructure had the effect of calming fears that the entire closure project was in service to cost-saving. In stark contrast to the situation that had occurred at the Michener Centre where the Michener employees gained the upper hand, the VVCTSC agreed that the transitions should proceed despite any stakeholder's economic interest.

Lacking the use of a citizen participation model, the Michener Centre stakeholders did not have the opportunity to develop a congruent philosophy on the needs of the Michener residents. The transition team for the Michener Centre remarked that: "[i]f they were only given a few more months, they would have succeeded".⁷⁹³ This confession was made in light of the fact that the Government of Alberta had expected the Michener Centre transition team to complete the closure within a single year, but also that the Michener Centre had been affected by strong opposition from various stakeholder groups such as the families of the Michener Centre

⁷⁹¹ CBC News.

⁷⁹² The Stakeholders, "Interview Data."

⁷⁹³ Baumann, "Direct Observation Notes."

residents; the employees of the Michener Centre and the labour union that represented them; and the Opposition Members of the Legislative Assembly of Alberta.^{794 795}

When Premier Prentice announced his decision to keep the Michener Centre open, he claimed his decision was based on his compassion for the residents, as well as inviting forty-six transitioned Michener residents to return to the facility.⁷⁹⁶ In doing so, Premier Prentice may have inadvertently sent a message that the decision to close had always been a purely economic one. Changes in policy are routinely motivated by financial considerations, but the reversed decision confirmed the criticism of the Michener closure.

In contravention of the values of inclusion, Premier Prentice spoke of how the residents required the protection of the Michener Centre, and in terms that upset many inclusion advocates:

All the residents will be permitted to live out their remaining years in this special place that has long been their home and where they have enjoyed the loving embrace of people who care for them. I have personally spent my life fighting to protect the rights of all Albertans. We will not close this facility on my watch. I think it is inhumane to relocate severely disabled Albertans from their homes in the Autumn of their lives.⁷⁹⁷

⁷⁹⁴ CBC News, "Critics Pan Decision to Close Centre for Disabled Adults: Red Deer's Michener Centre Hom to 125 Developmentally Challenged Clients."

⁷⁹⁵ CBC News, "Fight to Save Centre for Disabled Adults Continues: Relatives of Michener Centre Residents Want Historic Facility to Keep Operating," *CBC.Ca*, March 28, 2013, <https://www.cbc.ca/news/canada/calgary/fight-to-save-centre-for-disabled-adults-continues-1.1356414>.

⁷⁹⁶ CBC News, "Michener Centre Closure Halted: Premier Says 46 Residents Already Moved from the Red Deer Facility Will Be Allowed to Return," *CBC.Ca*, September 19, 2014, <https://www.cbc.ca/news/canada/edmonton/michener-centre-closure-halted-residents-allowed-to-return-1.2771739>.

⁷⁹⁷ Matt Dykstra, "Premier Jim Prentice to Re-Open and Re-Staff the Michener Centre for Developmentally-Disabled Adults," *Edmonton Sun*, September 19, 2014, <https://edmontonsun.com/2014/09/19/premier-jim-prentice-to-re-open-and-re-staff-the-michener-centre-for-developmentally-disabled-adults/wcm/9474a80e-58c0-44b1-bb24-a51a93f45f1f>; Otienna Ellwand, "Red Deer's Michener Centre to Remain Open under Prentice's Watch," *Edmonton Journal*, September 19, 2014, <https://edmontonjournal.com/news/politics/red-deers-michener-centre-to-remain-open-under-prentices-watch>.

Not only had Premier Prentice implied that institutionalisation remained a functional policy, but he was claiming that the Michener Centre was “a special place” that was preferable to community-based care. Furthermore, the Premier’s statement seemed to confirm that the necessary community infrastructure did not exist. In the end, the point of view from inclusion advocates was that the Government of Alberta had capitulated to the demands of the powerful labour union that represented the Michener Centre employee interests, rather than consider the human rights and welfare of the Michener Centre residents. Additionally, since the labour union had joined forces with the families of the Michener residents, and then each group had gained the support of the official opposition party, the Government of Alberta found itself obligated to end the closure project.

The decision to stop the transitions and keep the Michener Centre open was as shocking to the system as the initial announcement that the institutional facility would close. This is because the closure of Michener Centre was already well under way. Hundreds of Michener Employees had already been let go and given severance packages.⁷⁹⁸ There were contracts in place with community-based organisations to provide care for Michener Centre residents that would no longer be transitioning, and then three transitioned residents chose to return to the Michener Centre.⁷⁹⁹ There were even reports that transitioned residents were being transferred from group home to group home trying to find a good fit for them.⁸⁰⁰ Although the Michener team reported that there were many transition success stories, no formal evaluations of transitions were performed as the government hoped to avoid further negative attention.⁸⁰¹ One point that did manage to avoid media scrutiny is the fact that a reduction of nearly 50 Michener residents had

⁷⁹⁸ Baumann, “Direct Observation Notes.”

⁷⁹⁹ Baumann.

⁸⁰⁰ CBC News, “Deaths of Former Michener Centre Residents Prompt Calls for Investigation.”

⁸⁰¹ Baumann, “Direct Observation Notes.”

the effect of reducing the Michener Centre's economy of scale, meaning that the Government of Alberta is now paying more to keep Michener Centre open than it was before announcing the plan to close the institutional facility.

The main difference between the approach used by the Government of Saskatchewan and the Government of Alberta is the use of a citizen participation model. While the work of the VVCTSC represents an example of a citizen participation model that facilitates a high degree of citizen power, Alberta did not seem to utilise any model of citizen participation at all. Instead, the project to close the Michener Centre appears to have not only been attempted without consultation, but without internal research either, resulting in chaos.

Ultimately, the errors made by the Government of Alberta in its attempt to close the Michener Centre had enormous impact. It is not unreasonable to suggest that the relentlessly negative media attention, along with the strong and highly organised opposition campaign to keep the Michener Centre open, was a significant factor in the 2015 election loss of the Progressive Conservative Association of Alberta. This idea is supported by the statements issued by the Alberta Union of Provincial Employees where they credit the 2015 election results on their work in responding to:

successive attacks initiated by the Redford government on basic worker rights, on the right to bargain collectively, on public and private sector pensions, and on the workers, residents and families of Michener Centre. Thousands of members rallied, wrote to and met with their MLAs and attended public hearings to express their determined opposition to these matters. ...Bolstered by victories against legislated wage freezes and attacks on worker rights (Bills 45 and 46), cuts to public and private sector pensions (Bills 9 and 10). And the planned closure of the Michener Centre, AUPE members could see concrete proof that their concerted, collective action was getting results.⁸⁰²

⁸⁰² Merryn Edwards and Vanessa Bjerreskov, "The New Alberta Way," AUPE.org, 2019, <https://www.aupe.org/news/the-new-alberta-way/>.

Importantly, in the course of the Michener Centre closure project, the Government of Alberta had succeeded in pitting itself against all relevant stakeholders, which resulted in failure to achieve their goal. Had the Government of Alberta instead made use of an authentic citizen participation model where it was possible to build trusting relationships with other stakeholders, they would likely have succeeded at their task. Instead, the labour union that represented the Michener employees, a stakeholder group that stood to benefit from a failed closure, banded with Michener families to work toward keeping the Michener Centre open and succeeded in turning public opinion against the sitting government. Therefore, it is a significant risk for governments to forego stakeholder engagement, and the consequences of alienating stakeholders can be quite serious.

In the case of the closure of the Valley View Centre, the citizen stakeholders strongly asserted that adequate community living infrastructure is vital for a successful transition project. It is necessary to understand why this is the case, and there is likely no better example in Canada than the lack of community supports that exists in Nova Scotia. During the same period that the VVCFG, INSK, and the MSS worked together to perform a successful closure of the Valley View Centre, the social movement for inclusion in Nova Scotia faced extreme resistance from their provincial government. In a similar manner to how the Government of Alberta pitted itself against the Michener employees and the families of the Michener residents, the Government of Nova Scotia has pitted itself against inclusion advocates, as well as against people who have disabilities. Features of the Government of Nova Scotia's resistance ranged from the long-term confinement of people in the Nova Scotia Hospital's acute psychiatric lock down unit to the

Government of Nova Scotia asserting that people experiencing disability do not have a right to supported housing in the community.^{803 804}

For example, in 2016, there were 15 people residing in Emerald Hall, which is a lock-down ward in the Nova Scotia Hospital.⁸⁰⁵ All Emerald Hall residents experience ‘dual-diagnosis’, meaning that they are experiencing both intellectual disability and a mental illness, or a behavioural problem.⁸⁰⁶ Although Emerald Hall is meant only to serve as an acute short-term psychiatric treatment facility, residents are remaining there for many years because there is no other place for them to live or receive care.⁸⁰⁷ The government of Nova Scotia’s lack of will to create homes in the community has led to an extreme shortage of inclusive infrastructure. Nova Scotians who have intellectual disability and want a place in the community will each face several years on a waiting list occupied by 1500 people.⁸⁰⁸

Additionally, the government of Nova Scotia has taken great pains to resist the community inclusion of persons who have intellectual disability that goes beyond their choice not to provide inclusive community infrastructure. When faced with legal action and a human rights tribunal that was initiated by three institutionalised residents seeking permission to leave Emerald Hall, the government of Nova Scotia vigorously defended their refusal to fund

⁸⁰³ Jennifer Henderson, “Mom Pushes for More Help for Son Living at Nova Scotia Hospital: Mathew Meisner Has Been in Lock down for Almost 12 Years,” *CBC.Ca*, January 19, 2016.

⁸⁰⁴ CBC News, “Nova Scotia Argues That Supported Housing for Disabled Is Not a Right: Opening Arguments Begin at Human Rights Inquiry in Halifax,” *CBC.Ca*, 2018, <https://www.cbc.ca/news/canada/nova-scotia/disabled-institutions-community-care-human-rights-1.4520610>.

⁸⁰⁵ Henderson, “Mom Pushes for More Help for Son Living at Nova Scotia Hospital: Mathew Meisner Has Been in Lock down for Almost 12 Years.”

⁸⁰⁶ Henderson.

⁸⁰⁷ Henderson.

⁸⁰⁸ Robert Devet, “After Partial Win in Human Rights Case, Coalition Wants Affected People to File Human Rights Complaints,” *The Nova Scotia Advocate*, March 26, 2019, <https://nsadvocate.org/2019/03/26/after-partial-win-in-human-rights-case-coalition-wants-affected-people-to-file-human-rights-complaints/>.

supported community housing, claiming that supported housing was not a right.⁸⁰⁹ Of concern is that some residents of Nova Scotia institutional facilities are not permitted to leave, and most of those that have been given permission to leave cannot leave because there is no other place for them to go.⁸¹⁰ Ultimately, the Nova Scotia Human Rights Commission ruled that the three complainants had indeed had their rights violated, but the ruling did not extend to all Nova Scotians being held in an institutional facility.⁸¹¹ Nova Scotia Human Rights Board Chair Walter Thompson wrote that: “[e]ach disabled person’s circumstances must, in my opinion, be assessed individually and then a decision made whether the person has had ‘meaningful access’ to services”.⁸¹² Although the plaintiffs had achieved personal victory, other institutionalised persons that wished to live in the community would have to bring forward their own case to be heard by the tribunal. Vince Calderhead, the Legal Aid lawyer who represented the plaintiffs was disappointed, and he stated: “[i]t is unimaginable that a government in 2019 would seek to justify ongoing discrimination against members of the disadvantaged group, in this case people with disabilities. It simply can’t be the case that the government will be saying we can’t afford equality, we can’t afford inclusion for people with disabilities”.⁸¹³ The Government of Nova Scotia has chosen to appeal the ruling.⁸¹⁴

⁸⁰⁹ CBC News, “Nova Scotia Argues That Supported Housing for Disabled Is Not a Right: Opening Arguments Begin at Human Rights Inquiry in Halifax.”

⁸¹⁰ Robert Devet, “Many Stuck at East Coast Forensic Hospital for Years Because of Lack of Housing Supports, Human Rights Enquiry Hears,” *The Nova Scotia Advocate*, June 5, 2018, <https://nsadvocate.org/2018/06/05/many-stuck-at-east-coast-forensic-hospital-for-years-because-of-lack-of-housing-supports-human-rights-enquiry-hears/>.

⁸¹¹ Jean Laroche, “N.S. Human Rights Board Rules Province Discriminated against 3 Adults with Disabilities,” *CBC News*, March 5, 2019, <https://www.cbc.ca/news/canada/nova-scotia/disability-human-rights-beth-maclean-sheila-livingstone-1.5042441>.

⁸¹² Laroche.

⁸¹³ Laroche.

⁸¹⁴ Alexander Quon, “Court to Set Appeal Dates for Finding of Nova Scotia Human Rights Board Inquiry,” *Global News*, June 19, 2019, <https://globalnews.ca/news/5404798/board-of-inquiry-disabilities-ns/>.

The lack of community supports in Nova Scotia are easily illustrated. One Emerald Hall resident that experiences autism, Mathew Meisner, was 30 years old in 2016 and had lived in Emerald Hall for 12 years.⁸¹⁵ Meisner spends most of his days heavily medicated and sitting in a chair.⁸¹⁶ He will occasionally kick or throw objects, and for this reason, the clinical staff has determined that Meisner cannot participate in recreational activities because it is too dangerous for the caregivers.⁸¹⁷ Meisner has also been subjected to abuse while at Emerald Hall. In 2004 a caregiver: “lost his patience with Mathew, walked into the room, kicked him in the face and when Meisner attempted to get back up, he kicked him in the chest”.⁸¹⁸ Two caregivers were eventually convicted of assaulting Mr Meisner, and their employment was terminated.⁸¹⁹ Then, in 2016, Meisner was restrained in a time-out chair for two hours, which was in contravention of the facility’s restraint policy.⁸²⁰ Despite Meisner’s mother demanding that her son be moved to a more appropriate setting where he can receive appropriate therapy and recreation, the government of Nova Scotia has been slow to assist her. Ultimately, there is no other setting available for Mathew Meisner.⁸²¹

Beth Maclean is another resident of Emerald Hall that had trouble attaining a place in the community. Ms Maclean experiences mild intellectual disability and a mood disorder, which has resulted in her living at Emerald Hall for over 15 years.⁸²² She was also one of the plaintiffs in

⁸¹⁵ Henderson, “Mom Pushes for More Help for Son Living at Nova Scotia Hospital: Mathew Meisner Has Been in Lock down for Almost 12 Years.”

⁸¹⁶ Henderson.

⁸¹⁷ Henderson.

⁸¹⁸ Steve Silva, “Abuse Alleged at Nova Scotia Hospital’s Emerald Hall,” *Global News*, November 15, 2016, <https://globalnews.ca/news/3069516/abuse-alleged-at-nova-scotia-hospitals-emerald-hall/>.

⁸¹⁹ Henderson, “Mom Pushes for More Help for Son Living at Nova Scotia Hospital: Mathew Meisner Has Been in Lock down for Almost 12 Years.”

⁸²⁰ Silva, “Abuse Alleged at Nova Scotia Hospital’s Emerald Hall.”

⁸²¹ Henderson, “Mom Pushes for More Help for Son Living at Nova Scotia Hospital: Mathew Meisner Has Been in Lock down for Almost 12 Years.”

⁸²² Henderson.

the aforementioned human rights case where it was decided that Ms Maclean's rights had been violated.⁸²³ Beth Maclean has lived in institutional facilities since the age of 10, and since 2002, she has been kept in Emerald Hall where the staff had a practice of managing her behaviours by keeping her behind locked doors, occasionally in a padded room.⁸²⁴ Ms Maclean was originally sent to Emerald Hall after she hit a staff member at another institutional facility, but explains that she had hit the staff member out of frustration, because she had been locked up since 1986 and no one would let her leave. Although it is recognised that it was medically inappropriate for Ms Maclean to reside in Emerald Hall, and that it was desirable for her to be transitioned to the community as she was no longer in need of acute treatment, no alternative housing was made available.⁸²⁵ A Community Services Manager testified that she: "[u]rged the hospital to find approaches other than locking her in her room when she misbehaved", but this advice was ignored and Ms Maclean was never transitioned because community housing did not use locked quiet rooms.⁸²⁶ Of interest here is that the use of locked quiet rooms is not recognised as a best practice in care, and therefore contemporary community based care providers would not normally use this method of discipline. Yet, the persons in control of Beth Maclean's care and living arrangements seem determined to have her disciplined in such a way even after she were to leave Emerald Hall.

It is reasonable to conclude that the government of Nova Scotia, that continues to house more than a thousand people in large scale institutional facilities⁸²⁷, would have extreme

⁸²³ Quon, "Court to Set Appeal Dates for Finding of Nova Scotia Human Rights Board Inquiry."

⁸²⁴ Michael Tutton, "Woman with Disabilities Kept in Halifax Hospital for Years, Human Rights Inquiry Hears," *The Star*, June 18, 2018, <https://www.thestar.com/halifax/2018/06/18/woman-with-disabilities-kept-in-halifax-hospital-for-years-human-rights-inquiry-hears.html>.

⁸²⁵ Tutton.

⁸²⁶ Tutton.

⁸²⁷ Michael Tutton, "Groundbreaking Case Seeks to Make Supported Homes for Disabled Declared a Right," *CBC News*, February 4, 2018, <https://www.cbc.ca/news/canada/nova-scotia/human-rights-case-disabled-institution-supported-homes-1.4519077>.

difficulty de-institutionalising even a small portion of this population. Additionally, Nova Scotia continues to keep people who have intellectual disability in acute psychiatric facilities. The Government of Nova Scotia might make progress in aligning their social service delivery with the best practices in care that are contemporarily recognised by the medical community if they were to use a model of authentic citizen participation. Through consultation with relevant stakeholders, governments can gain the knowledge they need to make informed policy decisions. By ensuring that adequate and personal needs-based housing were in place before any transitions took place, the VVCTSC avoided the problems experienced by both Alberta and Nova Scotia.

Conclusion:

In the end, the Valley View Centre was closed to the satisfaction of most stakeholders. Not only have former Valley View residents and their families expressed happiness with their new living arrangements in the community, but multiple inclusion advocacy groups have expressed their approval of how the Valley View Centre was closed. The use of such a high level of citizen participation in policy construction is unusual in general, and unprecedented in other closures of institutional facilities within Canada. Still, the ‘Made in Saskatchewan’ approach to institutional facility closure worked and worked so well that it very likely can be replicated in other provinces. Most importantly, the ‘Made in Saskatchewan Approach’ worked because the Government of Saskatchewan partnered with the Valley View Centre Family Group to ensure that the individual needs of the Valley View residents would be properly met. As well, both the Government of Saskatchewan and the VVCFG were able to build a functioning relationship with INSK and trust INSK to provide accurate advice on how to improve conditions for the Valley View residents and build a system of care within the community that would serve to support former Valley View residents for the remainder of their lives. With the failures to

close other similar institutional facilities in mind, it is only through the efforts of the VVCFG and INSK that the Government of Saskatchewan succeeded in this project.

Chapter 7

Conclusion

Citizen Participation Leads to Successful Project Completion:

The closure of the Valley View Centre has been a measurable success. To the satisfaction of the Valley View Centre Family Group, friends and families of former Valley View residents, Inclusion Saskatchewan, and many other inclusion advocates, all the remaining Valley View residents were safely transitioned to care within the communities of their choice. This achievement is remarkable as the closure of an institutional facility is amongst the most difficult projects a government may undertake. Attempts to close institutional facilities have led to governments across Canada being faced with lawsuits from the families of residents, labour discontent, negative media attention, and the ire of inclusion advocacy organisations. Saskatchewan, however, took a different path than that taken by many other governments. By choosing to utilise the highest level of citizen participation, diverse stakeholders were able to co-construct the policy that would govern the closure of the Valley View Centre. This bold decision allowed the Government of Saskatchewan to avoid most of the perils that thwart other facility closures. The reward is that the Valley View Centre is now permanently closed with the former Valley View residents and their families reporting their satisfaction in receiving care in the community.

To their credit, the Government of Saskatchewan was shrewd enough to understand that their best chance at a successful closure meant forging a relationship with both the Valley View Centre Family Group and with Inclusion Saskatchewan. As these two groups had traditionally been at odds, the Government of Saskatchewan tread carefully to ensure that both factions would be satisfied with the outcome of the closure. As noted in the case of the Michener Centre in

Alberta, the families of the Michener residents formed a coalition with the Michener employees to successfully stop the closure of that facility. By giving the Valley View Centre Family Group a high measure of control over the closure process from the start, the Government of Saskatchewan avoided this trap.

In the case of Emerald Hall and their other facilities, the Government of Nova Scotia remains in extremely fractious relationships with the families of people who are institutionalised, the people who are institutionalised themselves, and with inclusion advocacy groups. Ultimately, the problem in Nova Scotia is that the government is unwilling, or unable, to invest adequately in the community care infrastructure that is required to support the closure of their institutional facilities. The Government of Saskatchewan, on the other hand, opened the purse wide enough to ensure that every remaining Valley View resident would have an appropriate place within the community. Furthermore, the Government of Saskatchewan has fully rejected policies of institutionalisation, and has fully embraced a policy of inclusion, something that the Government of Nova Scotia has been reluctant to do, even when in the processes of attempting to shut down facilities. Thus, it was appropriate levels of citizen control and financial investment that ensured the closure of the Valley View Centre, and it was both elements that led to success. The Government not only listened to the Valley View Family Group and Inclusion Saskatchewan in determining what was best for the remaining Valley View residents, but they made the appropriate financial investment in community-care infrastructure.

The successful closure of the Valley View Centre confirms that it is possible to complete the most difficult of projects while utilising the highest levels of citizen participation. What the Valley View Centre Transition Steering Committee achieved is highly remarkable and should stand as the ideal example of how to ethically close an institutional facility and create a system

of community care. There remains a significant number of institutional facilities in Canada and elsewhere that have defied closure, but there is now a pathway to success that can be easily implemented.

A Citizen Participation Model that Works:

A great deal has been written about numerous citizen participation models, and these models are often quite complicated in their design, with some others having limited effectiveness. The truth is, however, that a simply designed model will lead to success and in the end, the secret to successful citizen engagement involves governments merely asking the stakeholders what they need and then taking the answers seriously. This is what took place in the closure of the Valley View Centre. The result is that the Government of Saskatchewan achieved their goals, and the citizen stakeholders are pleased with the outcome.

There are various lessons to be learned from the successful closure of the Valley View Centre. The Government of Saskatchewan took specific steps that led to success, and these steps can potentially be replicated whether the project involves a closure of a similar institutional facility or is a much smaller project that concerns new municipal regulations for garbage collection. The first of these steps was identifying the most relevant stakeholders with which to create a partnership with. In the case of the closure of the Valley View Centre, the selection of stakeholder partners was the most important decision that the Government of Saskatchewan made. These stakeholder partners turned out to be the Valley View Centre Family Group and Inclusion Saskatchewan, two groups who had worked to repair past fractious relationships and concentrate on common goals. Importantly, these citizen stakeholders were the most likely to cause problems for the Government of Saskatchewan if there were any missteps, and that is the reason why it was imperative to create functioning relationships with them. If the Government

of Saskatchewan had failed to maintain relationships with the most relevant citizen stakeholders, the Valley View Centre might have suffered the fate of the Michener Centre closure project.

Once the relevant citizen stakeholder partners were identified, the second step was to give equally weighted positions on the project steering committee. It was this committee that worked together to come up with a plan on how to best close the Valley View Centre while collectively protecting the interests of every remaining Valley View resident. The committee itself represented various government policy analysts, Ministry of Social Services bureaucrats, family members of Valley View residents and the Valley View residents themselves, and experts in inclusion and community-living infrastructure, with two thirds of the committee being comprised of citizen stakeholders. Together, the members of the steering committee and their support staff created recommendations for Cabinet. Since all relevant stakeholders were involved in constructing the closure plan, Cabinet was assured that this plan, if implemented, would lead to success.

The third step in the process was for the Government of Saskatchewan to accept the recommendations of the committee and allocate the appropriate funding. Once Cabinet approved the recommendations and the associated budget to fulfil the recommendations, the project was underway and continued to its completion with only a minimum of resolvable conflict. The only task left was for the Government of Saskatchewan to ensure they kept their promise to fulfil the terms of the co-constructed closure plan.

To get the job done, the level of citizen participation utilised was of the highest possible form. The most vulnerable of the stakeholders, the Valley View Centre Family Group, were given pride of place and performed the role of Chair of the committee. Both the Family Group and the Ministry of Social Services carefully listened to Inclusion Saskatchewan about the best

practices in care and community living. Most importantly, they used their individual perspectives on the issue to co-construct policy recommendations that were agreeable to all parties, a just reward for adhering to this simple citizen participation framework. Ultimately, the project was such a success that it earned each Valley View Centre Transition Steering Committee member the ‘Premier’s Award for Excellence in Public Service’.

Welfare Markets Can be the Way, but not Necessarily the Way:

Although much of this dissertation has been centred on the establishment of welfare markets, it should not be assumed as an endorsement of either ‘privatisation’ or of the ‘Welfare State’. The Government of Saskatchewan chose privatisation as a tool with which to pursue de-institutionalisation, but this task could have been successfully performed with different economic tools. What allowed for the successful closure of the Valley View Centre was not the economic tools, but instead should be attributed to the willingness of the Government to facilitate a high level of citizen participation, and the ability of the Valley View Centre Transition Steering Committee members to direct decision making.

As governments have closed institutional facilities and replaced policies of institutionalisation with policies that are in support of care in the community, they have tended to rely on the establishment of health-care or welfare markets. The establishment of a welfare market is meant to ensure that appropriate levels of care are available to those who require them, and as many governments have done before them, the Government of Saskatchewan also chose to de-institutionalise through the establishment of welfare markets. Importantly, this decision was made as part of a larger project to restructure Saskatchewan’s economy that was based on specific economic ideology. There are, however, different models of creating community-care infrastructure, and therefore de-institutionalisation is not dependent upon the establishment of

privatised welfare markets. Nor should it be inferred that institutionalisation is the only style of care available within welfare states. While welfare markets and privatisation are very often promoted as the best methods of de-institutionalisation, there are many forms of economic organisation possible, and most types of economic organisation chosen would have the capacity to foster positive ideas about inclusion and the societal acceptance of people who have intellectual disability. Thus, the road ahead should avoid path dependency upon the ideological economic principles of welfare markets, but instead should allow for innovative solutions to specific challenges.

Reflection on the Past and Moving Forward:

When Saskatchewan joined Confederation in 1905, they were legitimising their role within the British Empire, and were exerting the values of that Empire. That included structuring the Saskatchewan economy based on British economic tools and social prescriptions, which included a policy of institutionalisation. Thus, Saskatchewan's policies of institutionalisation are a product of colonisation, while the process of de-institutionalisation of policies, attitudes, and people are products of de-colonisation. It is necessary to be wary still, as specific methods of de-institutionalisation remain as specific methods of colonisation. As Margaret Thatcher so eloquently described, the creation of welfare markets was the re-birth of British ingenuity and influence on the world, and she was correct as many governments have followed Britain's lead by similarly restructuring their economies. Still, there are other ways to de-institutionalise, and it is even possible to de-institutionalise within the structure of a strong welfare state, as several northern European nations have done. What is important is that Saskatchewan policies are developed that will improve the lives and well-being of its citizens first, while adherence to any prescribed economic ideology should come second. While the

exact structure of welfare markets differs whether they exist in the United Kingdom, The United States, or in Canada, it may be necessary to develop these markets differently even within a single country or even a single province. What may work very well in the Greater Toronto Region, may not work at all in most Saskatchewan communities. Likewise, what may work well in Saskatoon may not work at all in places like La Ronge or Estevan. Saskatchewan's diverse demographics and lengthy distances between remote communities is already recognised as a serious barrier to the provision of healthcare. Therefore, it is likely that an innovative and hybridised form of the typical welfare market structure may be required in Saskatchewan. Policy entrepreneurs should feel confident that they can improve on existing models and design something specific for Saskatchewan's needs.

The problems that have arisen within welfare markets have been diverse. It has been discovered that sub-standard service and the abuse of care receivers has been associated with care providers that receive sub-standard wages. It has also been asserted that welfare markets have not actually increased the availability of care in the community. Some care receivers in the United Kingdom complain of what has become colloquially referred to as the 'post code lottery' for care as funding is allocated by region rather than the numbers of people who require services. This has led to inequality between those who have access to care services and those who do not. In applying these issues to the Province of Saskatchewan, it is a concern that market pressures such as labour shortages and an unequal distribution of available workers makes it challenging to provide care services in remote areas of province. Thus, a 'post code lottery' for care has already developed within Saskatchewan, and welfare markets will be challenged to meet the demand.

As the Government of Saskatchewan will be aware, the newly formed welfare markets come with specific challenges that will eventually need to be overcome. For example, service providers in Saskatchewan have sometimes reported difficulty attracting and retaining skilled labour. Specific to the rural nature of many Saskatchewan communities, labour shortages are compounded when there is already a smaller pool of labour available to work in remote areas. As well, the Government of Saskatchewan would be wise to pay close attention to issues of training and remuneration for care givers to ensure that community based organisations will attract skilled and dedicated labour. Therefore, while the closure of the Valley View Centre was a stunning success, work is still required to ensure that community-living infrastructure will continue to meet the needs of Saskatchewan people who have intellectual disability.

Recommendations for the Future:

All levels of government in Saskatchewan should continue to use citizen participation in creating policy, especially the model that emerged out of the closure of the Valley View Centre. Use of high levels of citizen participation in Saskatchewan has proven itself to be a valuable tool that not only leads to success, but also enhances democracy and cooperation within the province. As with any detailed case study, questions quickly emerge about the degree to which the example is reproducible. The reality is that the VVCTSC followed a simple formula to achieve its goals. The VVCTSC consisted of a set of typical citizens and public servants who collectively solved one of the most difficult policy problems to solve. They were enabled to do so because the Government of Saskatchewan trusted the process. Continuing to trust in the process of authentic citizen participation enabled Saskatchewan to transcend the limits of ideology in order to solve a truly difficult problem.

Now that the Valley View Centre is permanently closed with all remaining residents successfully transitioned into the community, work must continue to ensure that adequate community infrastructure continues to exist for Saskatchewan citizens that require them. Two problems that plague welfare markets in general concern the tendering process and the ability of community based organisations to attract and retain skilled labour. For this reason, it is advisable that the Government of Saskatchewan ensures that the contract tendering process allows for the Ministry of Social Services to turn away organisations that have a history of poor service. The lowest bidding contractor is not necessarily the best contractor for the job.

Regarding labour shortages and the ability of community based organisations to attract skilled labour, the Government of Saskatchewan might consider developing a training program to ensure continuity of skills and ethics across the province. A program such as this would also increase the number of care workers available within the province, especially in remote communities. The Government of Saskatchewan might also consider regulating a minimum level of remuneration to ensure that qualified candidates seek employment as caregivers.

Inclusion advocates are advised to continue oversight of the transitioned Valley View residents, ensuring that their needs are indeed met for the remainder of their lives. The Government of Saskatchewan retains a moral and legal responsibility to ensure that these transitioned former Valley View residents, who were cared for under former policies of institutionalisation, will not now come to harm in the face of budget cuts or some unforeseen issue to arise.

If the Government of Saskatchewan continues to work with stakeholders at the highest levels of citizen participation, there is no doubt that former Premier Brad Wall will see his dream come to fruition: Saskatchewan will become the best place in Canada for people who have

disability to live. The closure of the Valley View Centre and the abandonment of policies of institutionalisation have moved Saskatchewan forward in ensuring that the best practices in care for people who have disability are pursued. These investments in community care infrastructure not only assist the former Valley View residents, but it also is of benefit to the whole community.

List of Abbreviations

CACL:	Canadian Association for Community Living
CBO:	Community Based Organisation
CCF:	Co-operative Commonwealth Federation
CLSD:	Community Living Service Delivery
DISC:	Saskatchewan Disability Income Support Coalition
GTM:	Grounded Theory Method
INSK:	Inclusion Saskatchewan
MSS:	Saskatchewan Ministry of Social Services
QUANGO:	Quasi-autonomous Non-Governmental Organisation
SACL:	Saskatchewan Association for Community Living
SAID:	Saskatchewan Assured Income for Disability
SAMR:	Saskatchewan Association for the Mentally Retarded
SARC:	Saskatchewan Association for Retarded Children
STS:	Saskatchewan Training School
VVC:	Valley View Centre
VVCFG:	Valley View Centre Family Group
VVCTSC:	Valley View Centre Transition Steering Committee

Appendix A

UNIVERSITY OF SASKATCHEWAN

To: Ken Coates

Professor and Canada Research Chair in Regional Innovation,
Johnson Shoyama Graduate School of Public Policy,
University of Saskatchewan

Student: Britt Baumann

Date: August 12, 2015

Re: BEH 15-232

Thank you for entitled: 'Collaborative Policy Construction and the Closure of the Valley View Centre Institutional Facility'. It has been deemed exempt as per Article 2.1 of the Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans, December 2010 that specifies "research may involve interaction with individuals who are not themselves the focus of the research in order to obtain information. Such individuals are not considered participants for the purposes of this Policy. This is distinct from situations where individuals are considered participants because they are themselves the focus of the research". It should be noted that though your project is exempt of ethics review, your project should be conducted in an ethical manner (i.e. in accordance with the information that you submitted). It should also be noted that any deviation from the original methodology and/or research question should be brought to the attention of the Behavioural Research Ethics Board for further review.

Please revise the consent form to reflect an exemption from the REB or delete any sections regarding REB approval.

Sincerely,

Behavioural Research Ethics Board

Appendix B

Participant Information Sheet

Project Title: Collaborative Policy Construction and the Closure of the Valley View' Centre Institutional Facility

Researcher: Britt Baumann, PhD. Candidate. Johnson Shoyama Graduate School of Public Policy, University of Saskatchewan. (303)202-7079. brb632@rmail.usask.ca

Supervisor: Dr Kenneth Coates, Johnson Shoyama Graduate School of Public Policy, University of Saskatchewan. (306)966-5136. kennethcoates@gmail.com

Research Participants:

Community Living Service Delivery ("CLSD") Disability Programs Division in Right of the Province of Saskatchewan as represented by the Ministry of Social Services (the "Ministry") and

SASKATCHEWAN ASSOCIATION FOR COMMUNITY LIVING, ("SACL")

Purpose and objective of Research: This research is about the closure of the Valley View Centre and how the government of Saskatchewan is working together with the Saskatchewan Association for Community Living, and the Valley View Centre Family Group. The purpose of the research is to gather valuable information about collaborative policy construction. Collaborative policy construction is when a government partners with stakeholders such as SACL and VVCFG in order to design new rules and procedures. The researcher's objective is to use the information obtained from this study to create a collaborative policy construction model that can be used in other situations, such as the closure of other institutional facilities. This collaborative policy construction model might become a tool for when governments require the assistance of stakeholders to design new policies.

Procedures: The researcher, **Britt Baumann**, will directly observe meetings, interview participants and analyse documents produced by the Ministry, SACL. their employees and representatives as part of a research program, which will become part of her eventual doctoral thesis. The approved research proposal has been provided to SACL and the Ministry.

Individual participants will be asked to participate by being personally interviewed by the researcher. These personal interviews make take up to 2 hours of the participants time.

Participants that agree to participate in personal interview will be digitally recorded. This digital recording will be transcribed by the researcher and then 'destroyed'. If the participant feels uncomfortable with being digitally recorded, the researcher can take written notes' during their interview instead. However, this procedure may lengthen the total time of the interview.

All individual participants should feel free to ask any questions they may have regarding the procedures and goals of the research, and/or the researcher's role. These questions may be asked at any time during the course of the research.

Participation is voluntary.

Potential Risks: There are no known or anticipated risks to you by participating in the research.

Potential Benefits: There are no known or anticipated benefits to you for participating in this study.

Confidentiality: Participants have the right to confidentiality concerning their involvement in the research, and therefore all participants will be anonymous. Steps will be taken so that it will be impossible to attribute particular data to individual participants. In order to ensure that participant identities are obscured, each participant will be assigned an alias. Furthermore, identities will be concealed through the random shuffling of responses so that it will be impossible to align any responses to any individual participant. Each participant will become a part of a composite description of a typical research participant.

Participants have the right to withdraw: All participants have the right to withdraw from the study at any time immediately before an individual interview begins and at the beginning of any steering committee meeting. If a participant chooses to withdraw, the interview will immediately conclude and any data obtained from the withdrawing participant will be immediately destroyed.

- Your participation is voluntary, and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Whether you choose to participate or not will have no effect on your position [e.g. employment, class standing, access to services] or how you will be treated.
- Should you wish to withdraw, the interview will immediately conclude and any data obtained from the withdrawing participant will be immediately destroyed.
- Your right to withdraw data from the study will apply until May 2016. After this date, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data.

Follow Up: A copy of the completed dissertation will be made available to the research participants. Additionally, a ‘plain language’ summary of the research results will be included for the use of participants.

Questions or Concerns:

- Contact the researcher(s) using the information at the top of page 1
- The University of Saskatchewan Research Ethics Board has deemed this research project to be exempt from oversight as per Article 2.1 of the Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans, December, 2010 that specifies “research may involve interaction with individuals who are not themselves the focus of the research in order to obtain

information. Such individuals are not considered participants for the purposes of this Policy. This is distinct from situations where individuals are considered participants because they are themselves the focus of the research.”

- Although this project is exempt of ethics review, the research will be conducted in an ethical manner as outlined above. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.officeusask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Appendix C

Checklist:

The draft manuscripts that I will share with the VVCTSC over the next few weeks are confidential and should not be shared with people outside of the committee or appropriate staff from Inclusion Saskatchewan. These draft manuscripts MAY contain errors. It is extremely important that I have appropriately represented your experiences and attitudes within my dissertation. Please verify that I have met my goal. If, for any reason, you feel uncomfortable about anything that I have written about you as an individual, Inclusion Saskatchewan, the VVCFG, the VVCTSC, or any other person or topic, please notify me so that I may make corrections. If corrections are required, I will revise the draft manuscripts to ensure that the VVCTSC is satisfied with the content.

Please check off the following questions:

- ☐ I feel confident that the author has accurately told the story of closing the VVC and transitioning Valley View residents into the community.
- ☐ I feel confident that the author has accurately described the work of the VVCTSC.
- ☐ I feel confident that the author has accurately represented the values of inclusion as promoted by Inclusion Saskatchewan.
- ☐ I am satisfied that the author has appropriately maintained the confidentiality of the research participants.
- ☐ I am satisfied that the author has protected the privacy of Valley View residents and their families.
- ☐ I am not satisfied, and I want the author to make some changes.

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